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THE RIGHTS OF AMERICA'S INSTITUTIONALIZED AGED: LOST IN CONFINEMENT

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ORIGINAL

HEARING

BEFORE THE

SUBCOMMITTEE ON
HEALTH AND LONG-TERM CARE

OF THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

FIRST SESSION

SEPTEMBER 18, 1985

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CONTENTS

Members Opening Statements

	Page
Chairman Claude Pepper	1
Mary Rose Oakar	21
Ralph Regula	21
Norman Sisisky	22
Mike Synar	23

Chronological List of Witnesses

Kirk Douglas, actor, Los Angeles, CA	23
Joseph Valley, Jr., son of former nursing home resident, Houston, TX	33
Ruby Seidler, 79-year-old nursing home resident, New York, NY	35
Janet Tulloch, 20-year nursing home resident, Washington, DC	39
Nursing Home Aide X, Washington, DC	40
Dr. Y, former corporate nursing home official	43
Neil F. Hartigan, attorney general, State of Illinois	57
Val Halamandaris, former Chief Investigator, U.S. Senate Special Committee on Aging; and Director of Oversight, U.S. House Select Committee on Aging; co-author "Too Old, Too Sick, Too Bad"	68
Richard Mahan, executive director, Commission on California State Government Organization and Economy, "Little Hoover Commission," Sacramento, CA	81
Roland Hornbostel, nursing home ombudsman, Cleveland, OH	103
Margaret Jacks, chair, Florida State Long-Term Care Ombudsman Coordinating Council, Tallahassee, FL	110
Patricia Nemore, attorney, National Senior Citizens Law Center, Washington, DC	120
Elma Holder, executive director, National Citizens Coalition for Nursing Home Reform, Washington, DC	128
Thomas Morford, Deputy Director, Health Standards and Quality Bureau, U.S. Health Care Financing Administration	129
Sheldon Goldberg, executive vice president, American Association of Homes for the Aging	134
Paul Willging, Ph.D., deputy executive vice president, American Health Care Association	139
Barbara Jameson, Ph.D., executive director, National Association of Residential Care Facilities	143

Appendix

Appendix 1. Additional material submitted for the record by Chairman Claude Pepper	149
Appendix 2. Additional material received for the record:	
Sheldon Goldberg, executive vice president, American Association of Homes for the Aging, letter	195
Paul Willging, Ph.D., deputy executive vice president, American Health Care Association, letter	197

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THE RIGHTS OF AMERICA'S INSTITUTIONALIZED AGED: LOST IN CONFINEMENT

WEDNESDAY, SEPTEMBER 18, 1985

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE,
Washington, DC.

The subcommittee met, pursuant to notice, at 9 a.m., in room 2359A, Rayburn House Office Building, Hon. Claude Pepper (chairman of the subcommittee) presiding.

Members present: Representatives Pepper, Oakar, Skelton, Synar, Regula, Schneider, Sisisky, Swindall, Lightfoot, Ridge, Boehlert, Wortley, and Meyers.

Staff present: Kathleen Gardner Cravedi, staff director; Melanie Modlin, assistant staff director; Peter Reinecke, research director; Mark Benedict, minority staff director; Lori Lightfoot, minority assistant staff director; Patricia Butch, congressional fellow; Robert Joy and Patrick McCarthy, detailees; Julia Kingston, staff assistant; Eve Subrin, Karen Wedding, and Kevin Dean, interns.

OPENING STATEMENT OF CHAIRMAN CLAUDE PEPPER

Mr. PEPPER. The subcommittee will come to order, please.

Ladies and gentlemen, members of the subcommittee, today's hearing has been called to examine allegations of abuse in our Nation's long-term care institutions. This subject is of immense importance to our subcommittee and to the people of the country because 1 out of every 9, or about 3 million people over the age of 65 are currently residing in our 44,000 nursing homes or the board and care type institutions across the land. Many of these now require help.

How well do they fare? The purpose of this hearing is to provide a thoughtful response to that question, and I want to compliment the staff on the excellence of the witnesses who will be here today and whom you will have the privilege to hear.

In May 1985, this subcommittee released a report entitled "Elder Abuse: A National Disgrace." Documents were given to show the shocking and increasing nature of abuse of the elderly, nationally, in the hands, too often, of their own family members. The subcommittee found that 1 out of every 25 elderly or about 1,100,000 people may be the victims of abuse from mild to extreme each year, and the number is increasing.

While the May 1985 investigation findings focused on elder abuse committed by members of the family, most often in the elderly per-

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son's own homes, the subcommittee was literally inundated with thousands of letters and phone calls indicating the extent to which abuse and violations of rights occur within the confines of long-term care institutions. These letters detailed case after case of abuses perpetrated against elderly institutionalized residents. They indicated that abuses ranging from the denial of the right to make basic personal choices, like when to get up and when to go to bed, what to eat and when, to horrid instances of physical and sexual abuse and neglect. Sometimes these latter cases resulted in death. The frequency with which these occurrences were reported was shocking.

This outcry of concern led the subcommittee to undertake an investigation to determine the status of institutional abuse in the United States today. We reviewed case histories of abuse brought to the subcommittee's attention over the past several years as well as hearings and reports on abuse of the elderly by congressional committees and administrative agencies. We conducted telephone interviews with abuse experts and researchers and surveyed literature, along with newspaper accounts of abuse in the possession of the Library of Congress. A telephone survey was also conducted of all State long-term care ombudsmen, persons appointed by the States to receive and investigate complaints of abuse, to ascertain their experience with this problem. An information paper, which I will ask be inserted in the record at this point, details this expert information provided to the subcommittee.

[The information paper submitted by Chairman Pepper follows:]

RIGHTS OF THE INSTITUTIONALIZED ELDERLY: LOST IN CONFINEMENT [1]

INTRODUCTION AND EXECUTIVE SUMMARY

On any given day in the United States, one out of every 9 elderly Americans, or 3 million people aged 65 and over, can be found in our nation's 45,000 nursing homes, board and care type facilities and mental hospitals across the country. They are among the most dependent and vulnerable in our society. How well do they fare? The purpose of this informational paper is to rsespond to that question. The response, in brief, is that many are forgotten and left to fend for their own rights.

In May 1985, the Subcommittee released a report entitled "Elder Abuse: A National Disgrace" documenting the shocking and increasing nature of abuse of the elderly at the hands of their family members and caregivers nationally. The Subcommittee found that one out of every 25 elderly, or 1,100,000 people, may be the victims of abuse—from mild to extreme—each year. This represents an increase of 100,000 abuse cases since 1981.

While the May 1985 investigation findings focused on abuse of the elderly at the hands of their loved ones and caregivers, most often in their own homes, the Subcommittee was literally inundated with thousands of letters and phone calls indicating the extent to which abuse and violation of rights also exists within the confinement of long-term care institutions. Elderly residents of these institutions, their families, friends and advocates, institutional caregivers, State and local government officials and other concerned citizens from coast to coast, detailed case after case of abuse perpetrated against the elderly institutionalized residents. They indicated that abuses—ranging from the denial of the right to make basic personal choices to horrid instances of physical and sexual abuse and neglect, resulting sometimes in death—are frequent occurrences.

This outcry of concern, coupled with volumes of research on elder abuse, including two congressional reports, congressional investigations spanning 2 decades, and over 9 hearings by the U.S. House Select Committee on Aging from 1979-1985,

[1] An Information Paper by the Chairman of the Subcommittee on Health and Long-Term Care, House Select Committee on Aging.

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spurred the Subcommittee on Health and Long-Term Care to determine the nature and extent to which abuses also occur within institutions nationwide. In the course of its investigation, the Subcommittee undertook the following steps:

Collected, reviewed and tabulated letters and case histories received by the Subcommittee over the past 7 years, as well as those received in response to the May 10, 1985, Subcommittee hearing and report, "Elder Abuse: A National Disgrace."

Reviewed all hearings and reports on protection of rights of institutionalized elderly by congressional Committees and administrative agencies.

Surveyed and interviewed, at the Chairman's request, enforcement officials, State and National advocates for the elderly, State nursing home commissions, and State long-term care Ombudsmen representing over 90 percent of institutionalized elderly.

Reviewed all books, periodicals, and newspaper and television references to abuses occurring in institutional settings in the possession of the Library of Congress' Congressional Research Service.

Collected and reviewed the latest available information regarding the number and characteristics of the institutionalized elderly population.

Collected, reviewed and catalogued nursing home admission agreements from facilities around the nation.

Reviewed Federal and State policies concerning the regulation of nursing homes and board and care facilities.

The Subcommittee found that one or more basic rights conferred upon all Americans by Federal statutes and the Constitution are often breached or violated by those entrusted with the residents' care. The Subcommittee found, for example, that about 1 out of every 7 institutionalized elderly persons may be the victim of physical or sexual abuse annually. The chance of physical abuse increases threefold upon entering an institution if compared to a recent Subcommittee finding that about 1 in 25 may suffer abuse at the nands of a loved one in the privacy of their own homes. The Subcommittee also found that 70 percent, or over 2 million elderly, may be denied the right to make simple basic personal choices like when to get up and when to go to sleep. The Subcommittee found that a profile of the institutional abuser emerges. The likely abuser will be the nursing home aide, who provides 90% of the care to nursing home residents. The aide is typically poorly educated, with little or no nursing experience, and is paid about the minimum wage—making, on the average, a little less than an employee making hamburgers for McDonald's—about $3.40 per hour. Interestingly, the Subcommittee learned that the violation of residents' rights is an increasing problem fueled by a number of national trends and federal policies, including the enactment of the new Medicare prospective payment system, further cuts in the Medicare and Medicaid and Supplemental Security Income programs, and a growing elderly population. The factors forcing these conclusions will be discussed in depth later in this information paper. Following are highlights of the Subcommittee's findings:

The violation of one or more basic rights is an "everyday fact of life" for many of our nation's 3 million institutionalized elderly. In an effort to determine the nature and extent of institutional abuse, the Subcommittee surveyed and obtained the views of State long-term care Ombudsmen representing about 90% of those currently institutionalized. The State Ombudsman is an appointed State employee who is charged with the responsibility of receiving and investigating allegations of institutional abuse. In essence, the Ombudsman acts as an advocate for the institutionalized within his or her State. The State Ombudsmen provided the Subcommittee with estimates on the annual incidence of abuse, by type of abuse, encountered by their States' institutionalized population. Their estimates were tabulated and averaged, and are detailed below:

75 percent, or 2.3 million, may be denied the simple right to complain and seek redress of problems and violations of rights out of fear of retribution and therefore often remain silent in the face of abuse and neglect.

70 percent, or 2 million of our institutionalized elderly, may be denied the right to make even basic person choices such as what and when to eat, when to wake up and go to sleep, and what to wear.

45 percent, or about 1.4 million, may be denied the basic right to privacy.

45 percent, or about 1.4 million, may be denied the basic right to maintain personal possessions; many are the victims of frequent thefts.

40 percent, or 1.2 million, may be the victims of verbal abuse.

35 percent, or about 1 million confined elderly may be denied adequate and appropriate medical and nursing care.

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25 percent, or 750,000 older Americans in institutions, may be denied the basic right of freedom of movement, being the victim of unnecessary physical and chemical restraints or simply not being allowed to leave his or her room.

20 percent, or 600,000, may be denied a safe and clean living environment.

20 percent, or 600,000, may be denied the right to freedom of speech, assembly and religion, by being denied access to visitors, ready access to a telephone, and access to religious services.

15 percent, or about one half million, may be the victims of physical or sexual abuse.

The majority of State Long-Term Care Ombudsmen responding to the Subcommittee's survey indicated that the violation of residents' rights is an increasing problem, and that a number of national trends and Federal policies are helping to fuel this growth. Some Ombudsmen pointed out that the new Medicare prospective payment system, referred to as the DRG (diagnosis-related groupings) system, is sending sicker patients, who require more skilled care, into nursing homes. Thus, nursing home staff are required to spend already limited time with a sicker and more dependent caseload. Cuts totaling $3 billion in real terms over the past 5 years have had a devastating effect on the Medicaid program, the payor of nearly half of the nation's nursing home costs. Coupled with limits placed on the Supplemental Security Income program, the primary funding source for board and care homes, this reduction in funds has put pressure on States to restrain reimbursement of nursing homes and has limited what board and care residents can pay. This in turn has resulted in some institutions dipping into quality of care services to maintain what security analysts consider already undeniable high profit margins. And, although the population most often requiring institutional care, those 85 and older, has grown by 30 percent over the past decade, Federal and State restrictions have limited the growth of nursing home beds to only 15 percent over the same period of time.

The Subcommittee found that those caring for nursing home residents are often ill trained, grossly overworked and very poorly paid. According to a recent National Academy of Sciences report, 4 of 5 nursing homes do not have a registered nurse on duty at all times, and the average number of registered nurses is 1 per 100 residents. In 1984, residents of skilled nursing facilities received about 1 hour and 43 minutes of direct care. Of this, an average of 12.5 minutes of direct care a day was rendered by registered nurses and 15 minutes from licensed practical nurses. From doctors, about 30 seconds of direct care per resident is given each day. The balance, or as much as 90 percent of all direct care given to elderly nursing home residents, is provided by unlicensed nurses' aides who typically are poorly educated and have little or no nursing experience. This group is paid, on the average, $3.40 per hour—less than the average McDonald's hamburger worker. Nurses' aides earn about half what the average janitor earns per hour, and little more than one third and one fourth of what prison guards and electricians earn, respectively. There is a constant turnover among aides, averaging 110 percent nationally. In addition, even though nurses' aides are qualified to perform only specific duties including feeding, dressing, and bathing patients, this information paper will show that chores that should be performed by doctors and nurses are often left to the aide, such as preparing and administering oral medications, suctioning patients' throats, applying indwelling catheters, counting apical pulses, and suctioning patients' noses.

In addition, the Subcommittee found that the Federal Government, which pays almost $10 billion of the nation's $33 billion nursing home bill each year, and billions more for the care of board and care and mental hospital residents, does little to protect the rights of its institutionalized elderly. There is no federally mandated "bill of rights" for the 1.5 million residents of board and care homes. The current federally mandated "patients' bill of rights" for residents of nursing homes is vague and hidden away as a subsection under rules for the governing body and management of nursing homes. It is of the same level as the requirement for nursing homes to have a written plan of action during a natural disaster. Under current Federal guidelines, violation of the right of a resident to be free from physical or mental abuse carries the same punitive action as the facility's failure to record the name of the utilization review committee in its minutes. The nursing home must submit a piece of paper telling how it intends to "corrrect the problem"—and nothing more. Federally mandated inspections of nursing homes are infrequent and facilities are often forewarned of impending inspections. Due to shortages of inspectors, some in-

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spections come only every 18 months. The Federal government does not require that those institutional employees who handle residents' money be bonded.

Lastly, during the course of its investigation the Subcommittee developed a series of policy options—for the Congress, for the Federal and State agencies, and for senior citizens and community groups—aimed at providing much needed improvements to our efforts nationally to protect the rights of the 3 million institutionalized elderly Americans. These recommendations include the following:

The Congress may wish to consider legislation tying the provision of any Federal funds to nursing homes to the assurance that nursing home residents are guaranteed the same basic rights that all Americans enjoy and that the violation of any of these rights be subject to the same penalties as would be appropriate for the same violations occurring outside of nursing homes.

The Congress may wish to consider legislation calling for the development of national standards (including residents rights) for board and care facilities.

The Congress may wish to consider legislation calling for the improved training and pay of nursing home caregivers, especially nurses' aides.

Federal and State inspection agencies should more actively enforce nursing home residents' rights requirements.

Federal, State and local law enforcement officials should take a more active role in investigating crimes occurring within institutions.

Community and service organizations, relatives and friends of residents and private citizens should take a more active role in nursing homes, board and care homes and mental hospitals in their communities.

The Congress should enact legislation establishing a national center for elder abuse and create incentives for States to strengthen their programs aimed at combating elder abuse.

The Congress should enact legislation requiring the bonding of all employees responsible with the handling of residents' personal funds in nursing homes, board and care homes and mental hospitals receiving any Federal funds.

The Congress should enact legislation requiring state Medicaid Fraud Control Units to investigate and prosecute cases of patient abuse and neglect.

The following information paper is an attempt to answer a number of critical questions regarding the protection of the rights of America's institutionalized elderly:

(1) Who Are America's Institutionalized Elderly?
(2) Who Cares For America's Institutionalized Elderly?
(3) What Rights Do The Institutionalized Elderly Forfeit?
(4) Why Do These Abuses Occur? Why Are They Increasing?
(5) What Is The Federal Government Doing To Safeguard the Rights Of The Institutionalized Elderly?
(6) What Can Be Done To Better Protect Their Rights?

(1) Who are America's institutionalized elderly?

On any given day one out of every nine elderly Americans can be found in institutions. These 3 million Americans over the age of 65 reside in the 45,000 nursing homes, board and care type facilities and mental hospitals around the nation. They are among the most vulnerable and dependent in our society.

There are approximately 1.5 million elderly Americans in this country's 14,000 nursing homes. An analysis of the latest national information paints the following profile of the file of average nursing home residents:

They are very old. Their average is 82.
They are female. Women outnumber men 3 to 1.
They are alone. 9 of 10 have no living spouse.
They are ill.
Most have chronic impairments:
Half have heart disease, hypertension, and/or arthritis;
Half may have some stage of Alzheimers' disease;
One third have impaired vision; and,
One third have impaired hearing.
They are very dependent:
9 of 10 require assistance being bathed;
7 of 10 require assistance being dressed;
1 of 2 require assistance being toileted;
1 of 3 require assistance eating;
4 of 10 have trouble or cannot control their bowel or bladder; and,
Many require help in all these areas.
They stay for a long time:

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7 of 10 stay longer than a year;
3 in 10 stay longer than 2 years; and,
2 in 10 stay longer than 5 years.

They don't leave:

Only one in five will return home;
Some will be transferred to hospitals; but, most will die in the nursing home.

As the result of the aging of the population and recent changes in the Medicare program, indications are that those in nursing homes today and in the future are even more ill and more dependent than as described above. This will be detailed later in this information paper.

Unfortunately, there is scant national information on the some 1.5 million residents of our nation's over 300,000 board and care facilities and 300 mental hospitals. Board and care residents tend to be somewhat younger and less physically impaired, yet many are mentally impaired. Indications are that the 1.5 million elderly residing in these facilities are older, sicker and more dependent today than in the past. Because of an increasing elderly population and a fairly constant number of nursing home beds, many elderly who previously would have been placed in nursing homes are now residing in board and care facilities for lack of anywhere else to go. Unless states and the federal government take steps to ease restrictions on the construction of new nursing home beds or increase the availability of noninstitutional care, this trend is likely to continue.

(2) Who cares for the institutionalized elderly?

As the previous information reveals, most of the 3 million elderly Americans residing in institutions are very dependent and require a great deal of care. The number needing skilled care is large and ever growing. The average American would be shocked to learn how little direct care these vulnerable people receive and who provides the bulk of this care.

According to a recent report of the National Academy of Sciences, residents of skilled nursing homes (the type of facility with the most stringent requirements for the amount and level of care to be given) receive an average of just more than 1 and a half hours of direct care each day. Even more startling is that despite the fact that most of these elderly are quite ill, they receive an average of 30 seconds of direct care a day from a physician. They receive 15 minutes or less of direct care daily from licensed or registered nurses. They receive the bulk of their direct care, an hour and 15 minutes a day, from unlicensed nurse aides. (See Table 1.)

While nurses aides provide up to 90 percent of all care to nursing home residents (skilled and unskilled), they are typically uneducated, new to the job, grossly overworked and underpaid, and have little, if any, room for advancement. 4 of 5 nursing homes do not have a registered nurse on duty at all times. All this comes with the approval of the Federal standards. The Federal Government requires no educational or work experience of nurses aides, yet allows these aides to provide any and all direct care to nursing homes residents without supervision from three o'clock in the afternoon until seven o'clock the next morning.

A routine list of tasks performed by nurses' aides in nursing homes runs the gamut from the very physical to the very technical. Nurses' aides bathe residents, dress residents, feed residents, toilet residents, lift residents, keep records of residents' food intake, temperature, pulse and respiration rate, among other things, and often also serves the role of housekeeper. They do it all. Not surprisingly then, as Table 2 reveals, nurses, aides are often also forced to perform tasks they are not qualified to carry out. Included in these tasks are the preparation and administration of medication, suctioning residents' throats and noses and taking and recording apical pulses. The results of this kind of unqualified care can be devastating.

Nursing home aides have historically been among the poorest paid in the workforce. Their salaries in no way reflect the intensity and range of care and services they are forced to provide. Sadly, today the typical nursing home aide—who is entrusted with providing the majority of care to very vulnerable and dependent elderly people—is paid less than the average McDonald's hamburger worker—about $3.40 an hour. As Table 3 indicates, aides' wages compare even less favorably to other common occupations. They are paid about half of what the average janitor earns, and about one third and one fourth of what prison guards and electricians earn. (See Table 3)

According to state ombudsmen there is little room for the average aide to advance, and increases in salary are few and far between. The comparison made by one nursing home aide several years ago is telling. She wrote, "It took six years, progressing in infinitesimal annual increments, before (an aide) would earn over

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$3.00 per hour. In other words, it took (an aide) the same amount of time to reach $3.00 per hour than it takes a young man to go through medical school and internship and into his residency."

Nurses' aides are frequently overworked. The subcommittee's investigation indicates that it is not uncommon for one nurse aide to be responsible for the care of 20 nursing home residents. It has come across instances of a single aide having to care for 50 and 100 residents at one time. Aides' work can therefore range from the hectic to the impossible.

With all these factors it is little wonder that aides do not stick on the job too long. Turnover is phenomenal among aides, with the annual rate averaging 110 percent nationally. It is also not surprising that nursing homes lose their aides to housekeeping, child care, factory and even migrant labor jobs.

Where are the doctors and nurses, the more educated and trained health care professionals? Doctors have historically spent little time in nursing homes, preferring hospitals and private practice. Although Federal regulations require nursing homes to have a medical director, each patient to have an attending physician, and physicians to review utilization, it is extremely rare that each would spend more than a few hours in the home during any one month. Most of the doctors' little time in nursing homes is spent reviewing and signing records, not visiting and examining residents. The result typically is that nursing home residents see a doctor for a 15 minute visit every two months—if that.

Registered nurses often direct the nursing staff in nursing homes. Because of this, most act in an administrative role. While most nursing homes have a registered nurse on duty during the day, 4 of 5 do not have them around the clock. In addition, there is an average of only one registered nurse to every 100 nursing home residents. They spend the majority of their time keeping and checking nursing and medical records. Little of their time is spent caring for residents.

While information regarding the care and those providing care in mental hospitals and board and care homes is very limited, data available to the Subcommittee indicate that conditions are likely to be worse in these facilities. There are no Federal requirements for the type of amount of care to be provided in these facilities.

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TABLE 1

WHO CARES FOR THE ELDERLY?

Direct Care Per Resident, Per Day*
By Type of Personnel

NURSES' AIDES
1 HOUR, 15 MINUTES

NURSES
27 MINUTES, 30 SECONDS

MEDICAL DOCTORS
30 SECONDS

TOTAL: 1 HOUR, 43 MINUTES

* Average for skilled nursing facilities.

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TABLE 2

Nurses' Aides Routine Duties

A. Patient Care Services:

- Bathes or assists residents to bathe
- Cares for residents' hair and nails
- Feeds or assists residents to eat
- Assists toileting of residents
- Keeps records of residents' food intake
- Takes and records residents' temperature, pulse and respiration rate
- Assists residents in dressing and undressing
- Assists residents in walking and moving wheelchairs

B. Other Services:

- Cleans room
- Makes bed

Tasks Performed By Nurses' Aides For Which They Are Unqualified

- Preparing and administering oral medications
- Suctioning patients' throats
- Applying indwelling catheters
- Counting apical pulses
- Suctioning patients' noses

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TABLE 3

Weekly Gross Income, 1984
Selected Occupations

Nursing Home Nurses' Aide	$ 136.00**
Hairdresser	201.82
Pest Exterminator	215.54
Janitor and Cleaner	235.54
Prison Guard	320.92
Elevator Operator	263.61
Auto Mechanic	301.43
Electrician	440.86

Source: Bureau of Labor Statistics, 1985 Unpublished Data

**Extrapolated From 1981 Data

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(3) What rights should our institutionalized elderly enjoy and how are these rights abused?

All Americans, whether young or old, rich or poor, well or sick, are invested with certain inalienable rights by the United States Constitution. Further rights are conferred by Federal statutes and the interpretation of them (and the Constitution) by Federal Courts. In addition, there are other rights which have been granted to citizens by their respective States through their legislatures and preserved through their courts.

In order to best assess how the rights of the institutionalized elderly are being honored or abrogated, the Subcommittee conducted interviews with representatives of the following groups: enforcement officials, State and national advocates for the elderly, State Attorneys General, State nursing home commissioners, and State long-term care ombudsmen, who represented over 90 percent of institutionalized elderly in this country. These persons were presented with a list of rights enumerated below—those which seemed particularly pertinent for institutionalized elderly—and asked to estimate the degree of abrogation of rights. They also were asked to share case examples relating to denial of rights, and their views on how to remedy the situation.

Ten basic rights of institutionalized elderly, and the degree to which each is violated nationally, are described below:

A. The right to complain and seek redress of grievances. Case histories received by the Subcommittee show that oftentimes seniors and their families are not allowed to complain or to seek redress of their grievances from facilities and/or government agencies. Attempts to do so may be met with threats of violence or with reprisals of all kinds, from outright expulsion from the facility to more subtle "punishments" such as receiving meals later. The Subcommittee found that approximately 75% are denied the right to complain or seek redress of grievances annually. The following are illustrative of violation of this right.

One Ombudsman from a Rocky Mountain state noted that family members told him not to investigate conditions in a home where their mother was being fed only twice daily and that nearly seven hours elapsed before aides cleaned the mess she made from a bowel discharge. They loved their mother but were unable to care for her at home. With that State having 99 percent of its nursing home beds occupied, they were afraid that eviction of their mother from this home where her rights were being abridged would mean she would have no place to go.

A source from a western state said that residents in one of that State's facilities were afraid to complain about conditions. Those who had complained in the past had their rent raised until they could no longer afford to live there.

A spokesman from a Pacific coast state observed that retribution can take many subtle forms. "If you know the people around you have the power to bring you a warm meal or serve yours to you last, when it's cold, and can get you to the bathroom on time or let you sit in your own waste, and turn you gently or with roughness, you soon learn not to make too many complaints."

B. The right to make basic personal choices. These are the day-to-day decisions taken for granted by those who live outside institution walls: what to eat and when to eat, what to wear, when to go to sleep and when to get up. If an institutionalized person is robbed of these choices, that individual can experience a numbness or unwelcome feeling of dependence. By being denied the right of making these choices, he or she is stripped of individuality and uniqueness. Abrogation of this basic right may contribute heavily toward mental illness, even where no symptoms were present on admission. The Subcommittee found that 70% of those institutionalized are denied the right to make basic choices. Case examples follow.

A midwestern state official commented that few residents of facilities in that state have any personal rights. Very frequently the decision making process is signed over, via the homes, to family members and other "reasonable people."

In one southern state, two homes routinely roused residents from bed between 4:00 and 4:30 a.m., and required them to go to bed between 5:00 and 5:30 p.m. These hours did not fit the normal sleep cycle of most residents, and they conflicted with visiting hours and other activities.

Clients at a western state nursing home were not allowed to turn on the lights in their rooms after dark. Also, the residents, once put to bed, were required to remain there until breakfast. The living room television was set on a specific channel selected by the owner, and no suggestions for variation were entertained.

Sometimes, denial of the right to make choices seems almost trivial: no sugar and cream for coffee at one home in Kentucky, a television was turned off

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promptly at 9:00 p.m. at a facility in Michigan. However, officials surveyed believed that such small factors—having the freedom to choose food and clothing, and hours of T.V. viewing and wakefulness—are critical to an individual's emotional well-being. Denial of these rights can produce in the resident a feeling of loss of power, which frequently translates into mental or physical illness.

C. The right to privacy. The U.S. Constitution and related laws recognize a right of all citizens to a certain sphere of privacy. Unfortunately, as can be seen from the examples which follow, privacy is very often denied to the elderly by their caregivers in institutions. Quite often the denial of privacy is used as a weapon in the psychological war against the elderly carried out by their caregivers. The number and choice of roommates, use of bathroom facilities in private, and provision of a place to have private meetings or conversations—all these would be basic rights of institutionalized individuals. Again, denial of this right can have severe emotional repercussions. The Subcommittee survey showed this to be a right violated by 45 percent of institutionalized elderly.

A woman seeking a possible home for her mother, came upon a deplorable situation in a New Mexico facility. Through a wide-open door, in plain view from the hallway, she could see an elderly woman, totally nude, tied to a portable potty chair. This woman was crying out for help. When the hall nurse was asked about the situation, she replied that they always stripped the lady down because she made such a mess of things.

A respondent from a middle Atlantic state noted that privacy in many of that State's institutions is a scarce commodity. Areas for private conversation are almost nonexistent and in some homes, even married couples are not permitted to sleep together. At those places which do allow this privilege, privacy is at a minimum and the residents are subjected to snide remarks and other harassment by staff.

D. The right to maintain personal possessions. Most would agree that it is reasonable for residents to have the right to select personal items to keep in their rooms. And, once these objects are brought in, residents should trust that they will not be stolen. The Subcommittee has received examples of residents being denied the right to keep even one personal possession in their rooms. In other cases, staff in institutions have taken the property of the elderly and converted it to their own use. Sometimes this has been accomplished by physical force or verbal abuse. In other instances, it has been accomplished by stealth, through deceit and fraud. As later examples will reveal, the elderly are all too often easy victims of schemes to deprive them of their money and personal property. This right was estimated denied to almost half of all institutionalized elderly in the Subcommittee survey.

An 82-year-old woman in an Illinois nursing home received 12 cotton housedresses and three pairs of slippers as Christmas gifts from her daughter and grandchildren. Within a month the clothing had all been taken away. In a letter to the Subcommittee, the daughter told us this was the fourth time this had happened at that facility. When the nursing home management was approached by family, their complaint was ignored.

In a New England state, a woman who had worked for over 30 years and who enjoyed a liberal pension suffered two broken hips at the age of 88. An acquaintance arranged for her to be placed in an unlicensed boarding home. Within two weeks, the owners had either forged the victim's name to checks or had forced her to sign over $2,300 in checks to them. The investigation revealed that the woman was purposely overmedicated in order to keep her in a stupor. It was later found that her generous holdings in stocks and bonds had also been misappropriated.

E. The right to freedom from verbal abuse. Many senior citizens are being verbally abused on a daily basis by their caregivers in institutions. This can range from relatively mild taunting and teasing to frightening profanity and threats. The seniors often feel that they have little choice but to put up with such abuse. They often believe that they are powerless to stop it and, should they try, it would mean that they would be denied care or food, or that they would be forced into the street. The survey showed that approximately 40 percent of institutionalized elderly are subjected to verbal abuse.

A comment from a southern state was that residents are viewed as the property of the nursing home. It is not looked upon as unusual when a resident is addressed in an abusive or patronizing way by staff.

The owner of a New Jersey nursing home was heard shouting at a resident, "You don't like it here? Get out!"

And the operator of a New Mexico home told an 88-year-old resident, "Your son is never going to take you out of here, no matter what. You're stuck here."

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F. The right to adequate and appropriate medical and nursing care. The right to prompt, high-quality medical care and the right to some participation in medical decisions are basic to Americans. The Subcommittee has learned of numerous examples where older persons have been deprived of medical care by staff in institutions. In some instances, persons who denied this care did not want to spend the institution's money. Sometimes proper medical care cannot be given because staff is too small or is not trained to meet the needs of the elderly. In some cases, it comes down to simple negligence. The tragic denial of this basic right was estimated to affect 35 percent of institutionalized elderly.

A respondent from a southern state said that over-medication is a commonly used restraint. All too frequently, drugs are used to replace the lack of staff. A sedated resident requires much less care than an alert one.

A source from an east coast state told of a frail elderly woman who was put in a tub of scalding water and never checked on, even though she screamed and was severely burned. After being removed from the tub, the woman was wrapped in sheets to conceal the burns and was never given treatment. She died from the burns.

In one southern state facility, a drug was administered an additional four weeks after the patient's physician administered it. The patient survived, although with temporary side effects.

G. The right to freedom of movement. The right to move freely, not to be imprisoned in one's room or in any small space, the right to be free from physical or chemical restraints unless absolutely necessary for medical reasons or reasons of security—these are at the very essence of American democracy. However, the Subcommittee has learned of numerous examples of older Americans being held captive against their will, virtual prisoners in the institutions which are their homes. There have also been cases of individuals who have been seriously over-medicated, restrained with ropes and wires, tied to their wheelchairs or beds, as well as locked in storage areas or their institution rooms. At least one fourth of older Americans in institutions are thought to have their movement restricted.

A response from a Rocky Mountain state mentioned several homes which have policies that clearly state "We won't tolerate wanderers." Obviously anyone walking the halls for whatever reason might be charged with this "offense."

Five senior citizens were found locked in the basement of a board and care facility. The basement was lit by two light bulbs and the people were fed two meager meals daily. They were coerced into signing over their Social Security checks to the proprietor. The basement smelled of urine and there were cockroaches all over.

A source in one midwestern state said that doctors have great power and can freely legislate a resident's mobility. "If a patient wants to go across the street to the K-Mart (a doctor's) permission is frequently required."

H. The right to a clean and safe living environment. This right is another which is breached with far-reaching consequences to the elderly. Lack of clean living conditions can often result in loss of personal dignity and respect among residents and, at worse, bring with it illness or even death. Respondents estimated that 20 percent of institutionalized elderly forfeit this right on a day-to-day basis.

An unlicensed New England board and care home was closed when officials found five elderly persons living in filth there. The home was littered with decaying food and dog urine and feces, and the temperature was about 55 degrees.

Health and safety problems in institutions are an all-too-common occurrence. In a northern state, the kitchen of a nursing home was being painted. Unfortunately, no drop cloth was used. Personnel saw paint spattering onto food but were told to serve it anyway.

The conditions to which residents of one home in a middle Atlantic state were subjected were nothing less than wretched. Visitors found one woman covered with her own excrement and no nurse or aides nearby. Improper turning of this resident meant that within two months of admission, her foot was eaten to the bone by a bedsore.

I. The right to freedom of speech, assembly, and religion. These protections, specifically enumerated in the Bill of Rights, have also been abridged and vitiated. In many instances older Americans have been prevented from communicating with family and friends. They have been denied telephone privileges. In several cases they have been denied access to the telephone and not allowed to receive mail unopened. They have been prevented from receiving visitors. In a number of cases reported, the elderly have been afraid to speak in front of their caretakers. They have been forbidden from speaking to their peers in the institutions and occasionally for-

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bidden to read the Bible or say grace at meals. This right, spelled out so clearly in the United States Constitution, is still thought to be denied to 20 percent of senior citizens in institutions.

Residents in one home in a western state have phone access, but it is far from private—the phone is located in the noisy dining room, next to the ice machine.

Mail delivery in some homes in one southern state is irregular. Mail often sits at the main desk or nurse's station for more than a week. It is also frequently opened, even if labeled "Personal."

Residents of one nursing home on the west coast are not allowed to "visit" with each other during the time when meals are served.

At one facility in the midwest, even silent grace at meals is forbidden. So are half-hour Bible tapes provided by a local clergyman.

J. The right to freedom from physical or sexual abuse. Physical abuse is conduct of violence which results in bodily harm or mental distress. It can include assault—putting the elderly person in fear of violence—at one end of the spectrum, all the way to murder and mayhem at the other end of the spectrum. Passive abuse—conduct which is careless—is known as negligence. Active abuse includes all manner of aggression against an elderly person in one's care.

Sexual abuse of the elderly by staff of institutions is a gruesome subject requiring no further definition. Examples below are sufficient to make the point.

Incidents of physical and sexual abuse are on the decline, but the Subcommittee survey shows that an alarming 15 percent of institutionalized elderly still may fall victim. Neglect falls under this category, being the passive form of physical abuse.

A nursing home on the Atlantic coast found it hard to have time to feed all its patients, and so many went without proper nourishment. One 66-year-old Alzheimer's patient died due to malnutrition and dehydration. (At the time of her death, she weighed 61 pounds.) The death certificate cited cardiac arrest as the cause.

A Pacific coast source tells of an elderly woman who was told that if she did not have sexual relations with the home operator, she would never see her family again. In another case at that home, an operator decided to teach an incontinent resident a lesson by taking him into the backyard, undressing him, and spraying him with a blast from a garden hose.

(4) Why do these abuses occur? Why are they increasing?

The Subcommittee found that the abuse of the 3 million elderly residing in nursing homes, board and care homes and mental hospitals is an increasing national problem. It found that federal health care cost containment policies coupled with national demographic trends are fueling this increase by putting more and more pressure on many already overworked and unqualified institutional caregivers. Our nation's long-term care institutions are being forced to care for sicker and more dependent residents with fewer beds and fewer staff.

As a way of reducing spiraling health care costs, the federal government implemented a prospective payment system for the Medicare program. Under this system, hospitals are paid a fixed amount set in advance per patient stay, based on the patient's diagnosis (DRG). In other words, what Medicare pays for hospital stays is no longer directly related to the actual costs of the care provided. Recent studies by the U.S. General Accounting Office and the Association of Area Agencies on Aging indicate that patients are being discharged from the hospital "sicker and quicker" under this new system. Thus those institutions providing post-hospital care are facing a much sicker and more dependent group of patients. At the same time, the population group most often needing institutional care, those 85 years of age and older, has skyrocketed. The U.S. Census Bureau estimates that this group of Americans 85+ will more than double from 1980 to 2000, increasing from 2.2 million to more than 5.1 million.

One would think that the proper response to this need would be to make more and more skilled care available. This has not been the case. Over the past 5 years, the Medicaid program, which provides the lion's share of the Federal government's payments for nursing home care, has suffered cuts in real terms of 10 percent or $3 billion. Substantial real cuts have also been made to the Supplemental Security Income program, which provides many millions of dollars annually to assist the residents of board and care facilities and mental hospitals. The Subcommittee found that this has led to cuts in the number of staff available to care for the institutionalized elderly. Thus, whereas many recognized the level and quality of staffing in long-term care institutions several years ago with smaller, less sick and less dependent institutional population, today the problem is much worse.

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Board and care home employees, nursing home aides, and mental hospital workers are often being forced to care for more people and sicker people they are not trained to competently help. Some nurses' aides are required to provide care for 50 residents. Some are applying catheter and administering medications. It is not difficult to understand how these types of situations are fertile ground for abuse.

The majority of respondents to the Subcommittee survey confirmed these findings, asserting that the violation of elderly residents' rights was on the rise. Thirty percent said that they did not believe the incidence was on the rise, yet many in this group said they were receiving more reports of violation of rights in institutions. They attribute this change to more publicity of such advocates as the long-term care ombudsmen offices, and increased awareness on the part of residents and their families as to their rights. They also offered the following comments indicating other problems and theories for the rise in abuse:

A senior advocate from a southern state pointed to demographics. As the older population swells, and the residents in nursing homes become older, frailer and sicker as a population, there will be an even greater decline in the ability of staff to provide necessary services. Something will have to give and, unfortunately, it will probably be residents' rights.

Another source in the south made this observation: The economic realities of health care are the focus now. When corners have to be cut to save money, the rights of residents are the first to go.

Some cite the underlying philosophy of many U.S. institutions as precipitating violations of rights "We've made a lot of headway. There's less physical abuse and the homes are generally more sanitary. But as long as the medical model persists, personal rights will continue to be abused."

Low pay of staff was mentioned frequently as a reason for improper treatment of residents. A source from an Atlantic coast state said that the only people you can hire for the kind of salaries that are paid in nursing homes have little interest in the welfare of older people—"and at those prices, why should they?"

Respondents in three States pointed out a new form of abuse making itself known: Medicaid discrimination. Crowded facilities are often unwilling or unable to accommodate indigent persons, especially if their health problems are serious.

A respondent from New England said that people are being discharged from hospitals in need of more medical care than supervisory care. Most nursing homes simply are not equipped to answer these needs. Also, there seems to be a rise in the number of mentally ill patents in all institutions for the elderly. There is a large increase in the need for heavy care.

A senior advocate in a western state expressed an often-repeated observation: Under the prospective payment system, people are being shifted back and forth between hospital and nursing home. The nursing home, having determined their need for special medical care, sends them to the hospital, which discharges them prematurely and returns them in their home sicker than before. Then, in order to quality for medicare, they are sent back to the nursing home with a new diagnosis, falling a new DRG category in order to qualify for additional payment.

A midwestern respondent echoed this view. People are returning to institutions from hospitals with IVs (intra-venous tubes), respirators, and in sore need of therapy. Nursing homes are not the place to provide such care.

A person in a Rocky Mountain state cited another problem. People who have exhausted their Medicare days in a hospital and who are desperate to get into nursing homes sometimes lie about their physical condition, making it out to be much better than it is. They're admitted to the nursing home, which soon discovers that it has neither staff nor equipment to meet their health needs.

In parts of some States, incidence of nursing homes *not* taking people is very high. These are usually the rural or isolated areas. Facilities in these places have fewer beds to begin with the people in need of their services simply have no place to go.

A view from the midwest is that doctors need to be better educated to understand the different levels of skilled care. They aren't fully aware of the fate they condemn elderly people to endure if they release these persons from the hospital prematurely.

A representative from another midwestern state told the Subcommittee that there is a 15-day hold on the bed of a person who goes from a nursing home into a hospital. After that time, if the person is not willing or able to pay out-of-pocket what Medicare doesn't cover, his or her bed can literally be sold out

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from under him/her. Thus, people are desperate to get out of hospitals, even if they are still sick, and back to their nursing homes as soon as possible. They need to save their place to sleep.

(5) What is the Federal Government doing to safeguard the rights of America's institutionalized elderly?

Although the Federal government will spend upwards of $10 billion this year through the Medicare and medicaid programs for nursing home care billions more through the Medicaid programs for nursing home care and billions more through the Supplemental Security Income program for board and care and mental hospital care, its system for safeguarding the rights of the 3 million elderly residents of these facilities is limited at best. It is a system which has allowed the abuses described in this report to persist and increase.

The Federal government has set minimum standards which must be met by nursing homes in order to receive Medicaid or Medicare funds. These standards, called "conditions of participation," cover a range of areas from nursing care to pest control, from dietary care to medical care. Hidden away in Federal regulations under the area of requirements for a nursing home's governing body and management, is a lower level requirement for the protection of residents' rights. This vaguely worded requirement, which one would suppose to be the most important and basic of all requirements, in on the same level in federal regulations as the requirement for a written plan of action in case of a natural disaster.

Federal law also requires that nursing homes be inspected annually for compliance with these standards. Because of Federal cutbacks, however, some facilities are inspected only every 18 months. Often facilities have advance knowledge of impending inspections. Experts have agreed that this allows facilities to "fix things up" before inspectors arrive.

Even more incredible if an inspector finds that a resident's right to be free from physical or mental abuse has been violated, the only formal action required is for the nursing home to provide an "acceptable" written explanation as to how they intend to "correct the problem"—nothing more. Follow-up visits have ofter been replaced by phone calls to the facilities.

Those surveyed by the Subcommittee confirmed its findings. Nearly 90 percent of those surveyed told the Subcommittee that government inspections are not effective in protecting nursing home residents' rights. Some of their comments and suggestions follow:

An official from a midwestern state said that nursing home inspections are not frequent enough. Because of a shortage of inspectors, some nursing homes conduct their "annual" inspections every 18 months. And, even though the yearly inspection is often delayed, a shrewed administrator can easily approximate the time of inspection and make short-term changes in conditions. This person recommended that inspections be staggered, so as to present the inspector with a realistic picture of the institution, in its usual pattern of operation.

A source from a southern state expressed similar concerns. "There is a desperate need for additional inspection staff. Our entire State has only eight inspectors."

A western state source said that inspectors serve more as consultants than in their designated role as enforcers. She suggested a greater role for lawyers, who should be contaced to investigate such violations as theft. This would draw more public attention to abuses in institutions, and compel inspectors to be more thorough in their investigations.

There are currently no Federal standards for inspection of board and care facilities. The Federal government has no real check on the care provided in these facilities. It has shied away from involvement in board and care homes for fear that the costs may be too large. Yet, dependent elderly Americans continue to be victimized.

(6) What can be done to protect the rights of America's institutionalized elderly?

This information paper identifies a number of very serious problems. These are problems that will not simply go away. Left unchecked, they will only get worse—at the expense of the lives and the quality of life of those who are among the most dependent and vulnerable in our society. Swift and determined action is required to begin to address the widespread violation of rights of this nation's 3 million elderly residents of long-term care institutions. Throughout the course of its investigation, the Subcommittee has developed a series of policy options—for the Congress, for the Federal and State agencies, and for senior citizens and community groups—aimed at providing much needed improvements in our national effort to safeguard these rights. These recommendations include the following:

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The Congress may wish to consider legislation tying the provision of any Federal funds to nursing homes to the assurance that nursing homes are guaranteed the same basic rights that all Americans enjoy and that the violation of any of these rights be subject to the same penalties as would be appropriate for the same violations occurring outside of nursing homes.

The Congress may wish to consider legislation calling for the development of national standards (including residents' rights) for board and care facilities.

The Congress may wish to consider legislation calling for the improved training and pay of nursing home caregivers, especially nurses' aides.

The Congress may wish to consider legislation to reform Federal nursing home standards.

Federal and State inspection agencies should more actively enforce nursing home residents' rights requirements.

Federal, State and local law enforcement officials should take a more active role in investigating crimes occurring within institutions.

Community and service organizations, relatives and friends of residents and private citizens should take a more active role in nursing homes, board and care homes and mental hospitals around them.

The Congress should enact legislation establishing a national center for elder abuse and creating incentives for States to strengthen their programs aimed at combatting elder abuse.

The Congress should enact legislation requiring the bonding of all employees responsible for the handling of residents' personal funds in nursing homes, board and care homes and mental hospitals receiving any Federal funds.

The Congress should enact legislation requiring state Medicaid Fraud Control Units to investigate and prosecute cases of patient abuse and neglect.

Mr. PEPPER. The results, sad to say, were shocking. The bottom line is that when many senior citizens enter long-term care institutions, they check their rights at the door. Our survey revealed that the violation of one or more basic rights is almost an everyday fact of life for many elderly in these institutions. We were told in any given year, 75 percent of institutionalized elderly, or 2.3 million people may be denied the simple right to complain and seek redress of their problems and violations of rights out of fear of retribution and, therefore, often remain silent in the face of abuse and cruelty.

Seventy percent, or 2 million of our institutionalized elderly may be denied the right to make even basic personal choices, such as what to eat and when, or when to wake up and when to go to bed, and what to wear.

Forty-five percent, or about 1.4 million, may be denied the basic right to privacy. Forty-five percent, or about 1.4 million may be denied the basic right to maintain personal possessions and many are the victims of frequent thefts. We will have evidence of that in a moment.

Forty percent, or 1.2 million may be the victims of verbal abuse. Thirty-five percent, or about 1 million confined elderly may be denied adequate or appropriate medical or nursing care. Twenty-five percent, or 750,000 older Americans in institutions may be denied the basic right of freedom of movement, being the victim of unnecessary physical and chemical restraint or simply not being allowed to leave their rooms.

Twenty percent, or 600,000 may be denied the right to freedom of speech, assembly, or religion, by being denied access to visitors, ready access to a telephone, or access to religious services.

Another 15 percent, or about one-half million may be the victims of physical or sexual abuse. Why do these terrible things occur and why are they increasing?

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Four out of five nursing homes do not have a registered nurse on duty at all times, and the average number of registered nurses was 1 per 100 residents in 1984. Residents of skilled nursing facilities receive about 1 hour and 43 minutes of direct care per day. Of this, an average of 12.5 minutes of direct care a day is rendered by registered nurses, and 15 minutes a day from licensed practical nurses. That is the total amount of what you might call professional care. The amount of direct care by doctors per resident per day is about 30 seconds. The balance, as much as 90 percent of all direct care, given to elderly nursing home residents, is provided by unlicensed nursing aides.

It is no wonder that aides are usually the ones who perpetrate abuses. They are clearly overworked, typically they are poorly educated, with little or no nursing education or experience, and they are paid on the average about $3.40 an hour, less than the average McDonald's hamburger worker makes. Think about it. We pay on the average about a $136 a week for an aide to care for our loved ones, your fathers and mothers, and about 2½ times that amount for a prison guard; $320 a week to care for our Nation's convicted criminals. There is a constant turnover among these aides. About 110 percent per year. This is not surprising after we learn they care for an average of 20 extremely debilitated patients a day.

Supposedly, the nurses' aides feed, dress, walk, and bathe residents as well as record temperatures and maintain the resident's personal hygiene. The typical aide performs these tasks as well as chores that should be performed by qualified doctors and nurses, such as preparing and administering oral medication, suctioning patients' throats, applying in-dwelling catheters, counting pulses, and suctioning patients' noses. It is hard to imagine how one person can provide all these tasks daily for 20 or more patients. It is not hard to see why they would fail to do so a good job and why they often take out their frustrations on these poor, helpless people they are bound to serve.

Sadly, the subcommittee found that the Federal Government, which pays almost $10 billion of the Nation's $33 billion bill for institutional care of the elderly is doing relatively little to protect the rights of the institutionalized elderly. That is one of the main reasons why we are holding this hearing today, to show the facts to the people, and to let the people stimulate the Congress to direct action to see that protection is afforded these people in the appropriate way. We will discuss the appropriate means later.

Interestingly, abusive treatment of our elderly at the hands of underpaid, ill-trained, and overworked institutional caretakers is not likely to abate. According to ombudsmen, certain national trends and Federal policies will exacerbate an already serious situation.

The new DRG system is moving elderly out of hospitals quicker and into institutions sicker. This, combined with the growing elderly population and cuts of over $3 billion in the Medicaid Program, and I noticed in the paper this morning it was proposed in the other body to cut Medicare benefits $11 million over the next 2 years, these two cuts lead to reductions in quality of care to maintain what security analysts call undeniably rich profit margins.

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The obvious question at this point is what the Federal Government can do to prevent the abuse of institutionalized elderly. Not only what can we do ourselves, but what can we induce the States to do to be more effective in the protection that they extend.

I have suggested to the Governor of Florida that more of the inspectors of these institutions be elderly people. I think they would be more sympathetic to those in the facilities they inspect and whose benefits they seek to achieve.

At a minimum, the Congress should require that Federal regulations covering nursing home care include a patient's bill of rights in its conditions of participation in order that violation of these rights can bring the same punitive sanctions available under the law as identical violations receive when they occur in the privacy of our homes.

In addition, facilities should be required to be inspected annually and without notice to a facility. Some of our witnesses today will detail first hand their unfortunate experiences in trying to obtain care in our Nation's long-term care institutions. Others will recount their frustrations in attempting to bring about reform.

Still others will give dimensions to this increasing national problem.

We will also hear from the administration and the nursing home industry.

I look forward to their suggestions to address our findings. Last, I look forward to the testimony of our distinguished leadoff witness, a man who really needs no introduction.

But, let me say with pride, a few weeks ago, while reading the New York Times, I was impressed by an article entitled "Abuse of the Elderly Must End." That, I noticed, was not written by a social philosopher or the head of some great institution. This was written by one of the great actors of our country, a great American who has, for a long time, been, with great approval, approbation, and appreciation, a favorite of the American people.

It is a very concise and well presented opinion which I would like to have entered, without objection, at this point, in the record of this hearing.

[The material submitted by Chairman Pepper follows:]

[From the New York Times, Aug. 20, 1985]

ABUSE OF THE AGED MUST END

(By Kirk Douglas)

BEVERLY HILLS, CA.—I recently became aware of a serious problem in this country while working on a film that takes place in a nursing home where the patients are systematically abused. Some of the abuses in the script shocked me, and I assumed they had been exaggerated for dramatic purposes. I was devastated when I found out that the reverse is true: the abuses had been toned down to make them acceptable on television.

More than one million elderly Americans are abused every year, in nursing homes and in their own homes, at the hands of unkind strangers and unscrupulous relatives.

Elder abuse is physical. The elderly are beaten, burned, raped, deprived of food and liquids, or left to die in their own waste. They are punished with cattle prods. Experimental drugs are slipped into their food without their knowledge or consent. The elderly are killed, deliberately or by neglect, by people who assert that the old are better off dead anyway.

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Elder abuse is emotional. They are told they are crazy, tied to wheelchairs in closets, forced to eat out of the dog's dish. They accept degradation to keep a roof over their heads.

Elder abuse is financial. The Government used to mail thousands of dollars of other people's Social Security benefits to the Rev. Jim Jones every month at his camp in Guyana, and never questioned what he was doing with the money. Over an 11-year period, a woman embezzled $173,000 from 32 elderly servicemen living at the United States Soldiers' and Airmen's Home in Washington. Time after time, older people have granted power of attorney to a friend or relative—who then takes everything the older person has.

How has this been allowed to happen? Nobody cared—largely because in America, "old" is a dirty word, and it happens to somebody else. Governor Richard D. Lamm of Colorado could say that the elderly have a "duty to die and get out of the way" because Americans have a stereotypical—and false—image of the elderly as useless and waiting to die.

We ignore the vast numbers of elderly who continue to grow and learn, to share the expertise of a lifetime with others. Americans ignore the fact that their own President is 74 years old. And so the abuse increases, by 100,000 new cases every year since 1981. State laws are inconsistent as to who is required to report abuse of the elderly, and what the penalties are for not reporting. There is no national law requiring the reporting of elder abuse.

Three bills now before Congress would begin to rectify this situation. One would require investigation of criminal cases of abuse and neglect in homes receiving Medicaid funds. An other would require that facilities receiving Medicare and Medicaid payments post bonds to assure the security of patients' funds. A third would establish a National Center on Elder Abuse.

The support of all Americans, old and young, is needed to pass these bills. It took Congress 100 years to pass a national law on child abuse, after the American Society for the Prevention of Cruelty to Animals argued before the Supreme Court that a child is a member of the animal kingdom, too, and thus is entitled to the same rights as any other animals. The A.S.P.C.A. argued the case in 1874; Congress passed the law in 1974.

We cannot wait 100 years to deal with elder abuse. At the beginning of this century, only one in 16 Americans was over 60. By the beginning of the next century, one of every four Americans will be over 60. If we wait, by the time our children grow old, they won't stand a chance.

Mr. PEPPER. At the invitation of this subcommittee, the author of this editorial has graciously and at his own expense agreed to come to Washington and testify before us today. This is the first time this committee, and I think probably any committee in the Congress, has had so many people request that we have a witness at a very important hearing rather than the staff selecting the witness. Ultimately, they did that, but the people were coming in with many, many requests.

This is a man who knows about this subject. We know he can help us. So, at the invitation of this subcommittee, the author of this editorial has graciously come here to be a witness for us today.

Over the years, most of us have become familiar with this man as a great actor, who has made more than 70 pictures. It is his most recent role as Amos that was the genesis of this article. He has traveled extensively on behalf of the State Department through China and Pakistan, through the Eastern bloc nations in Europe and through South America, discussing openly his pride in our Nation and its way of life. His activities have twice before generated articles in the Congressional Record.

For these travels, he has also received the highest civilian award this country can bestow, the Presidential Medal of Freedom.

We have before us today, a man who is not afraid to speak out for this country's greatness or against its shortcomings. But before I introduce this distinguished speaker, I would like to know how

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many of the members of the subcommittee would like to make a statement for the record?

Ms. Oakar, would you like to?

STATEMENT OF REPRESENTATIVE MARY ROSE OAKAR

Ms. OAKAR. Mr. Chairman, first of all, I just wanted to say that although everyone may know this, you are the leader in our country on behalf of our older Americans. It was 6 years ago that we had a hearing on elderly abuse. We have been having hearings on this subject over and over again.

We heard from people who talked about the 98-year-old woman who was in a nursing home and sexually abused. We heard from people who were mentally and physically abused by members of their own family.

We learned of this crisis situation, and it was on that day that you and I, Mr. Chairman, introduced the Elderly Abuse Prevention Act, trying to establish a national clearinghouse on elder abuse such as the one that we have for child abuse, and trying to give the States incentives to do things about this situation.

We know that very often people are not granted immunity from testifying or bringing forward information regarding elder abuse. As a result, elder abuse is one of the best kept secrets in our country.

Mr. Chairman, I hope that because of the deep interest of our guests, Congress will take the lead in doing something about this problem. Mr. Douglas is one of the finest American performers, and we are most proud of him. His presence today also shows what a great humanitarian he is. I see Jack Valenti in the audience, who is a spokesman for the motion picture industry, and Mr. Douglas' son, who is a very fine artist in his own right. With this celebrity interest, I hope awareness will be raised on the seriousness of this problem.

We ought not to need to continue hearings on the issue. We know it is out there. It is time to pass the legislation and to get down to real business. Mr. Chairman, I wish to commend you for having the patience to keep onward with these problems. I will be with you every step of the way, until we finally pass some legislation related to this issue.

Mr. PEPPER. Ms. Oakar, the record shows that you have been one of the pioneers in efforts against elder abuse, and we are finally going to get something done about it.

Mr. Regula.

Mr. REGULA. Thank you, Mr. Chairman, and I ask unanimous consent for my statement to be made a part of the record.

Mr. PEPPER. Without objection, so ordered.

[The prepared statement of Mr. Regula follows:]

PREPARED STATEMENT OF REPRESENTATIVE RALPH REGULA

Mr. Chairman, and distinguished members of the subcommittee I would like to take this opportunity to express my sincere concern over the difficult issue of elder abuse within the institutional setting. The gentleman from Florida should be commended on his efforts in bringing together this distinguished assemblage of experts and personalities.

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Approximately 3 million older Americans, over the age of 65, reside in the 45,000 nursing homes, board care type facilities and mental hospitals around the nation. Of this total 1.5 million elderly reside in 14,000 nursing homes.

The chairman's investigation and resulting report is part of a growing consensus that many of these elderly who live within the institutional setting require protections and services not currently in place within the long-term care industry. Ranging from the approximately 2.3 million denied basic personal choices to the one half million who are the victims of physical and sexual abuse the seriousness of the problem is becoming recognized by the public.

Many reasons have been cited regarding the cause of abuse to nursing home residents. Elder abuse has been allegedly linked to the quality of staff; proper allocation of resources; lack of a national mechanism to protect the rights of residents and even the recent program changes in Medicare, Medicaid, and Supplemental Security Income. Common sense reveals the credibility of some of these contentions but others are less persuasive.

A question at the core of resolving institutional elder abuse is who is responsible, and to what degree, for responding to the problem. Under current law basic licensure and quality control is the jurisdiction of the States with supervision by the Federal government. The Federal government sets minimum standards which must be met by nursing homes in order to receive Medicaid or Medicare dollars. These standards, called "conditions of participation", range from nursing care to pest control, from dietary care to medical care. But it is the State which retains the overall responsibility for quality of care and patient rights.

In March, the California Assembly passed into law legislation which would strengthen penalties for the abuse of patients and increase Medi-Cal payments to nursing homes. More recently, the Washington, D.C. City Council considered a bill that would require the District government to inspect nursing homes at the request of patients and to levy fines of up to $5,000 a day to force improvements. Such efforts by State and local governments are typical of their ongoing concern with long-term care.

I am confident the testimony of our distinguished witnesses will provide an insight into some of the causes and possible responses to be taken by Federal and State governments, and the long-term care industry regarding this important matter.

Mr. REGULA. As has been pointed out by my colleague from Ohio, we have had a lot of hearings, a lot of rhetoric, but not a whole lot of action, and I think it is time for some action.

I yield.

Mr. PEPPER. Thank you, Mr. Regula.

The Honorable Mike Synar. Ms. Schneider.

Ms. SCHNEIDER. No, thank you.

Mr. PEPPER. Thank you, Ms. Schneider. Mr. Sisisky.

Mr. SISISKY. Yes, Mr. Chairman.

I would ask unanimous consent that my statement be included in the record.

Mr. PEPPER. Without objection, it will be received.

Mr. SISISKY. Thank you.

[The prepared statement of Mr. Sisisky follows:]

PREPARED STATEMENT OF REPRESENTATIVE NORMAN SISISKY

Thank you Mr. Chairman, and first, allow me to commend you for calling this hearing and assembling such distinguished witnesses to focus on the quality of institutionalized care for approximately 3 million of our nation's senior citizens.

Over and over again I have been amazed at the Subcommittee's discoveries of elder abuse and its prevalence throughout the United States and have asked myself, "How can this be?" I was shocked to learn of the number of cases of abuse by family members, which I believe occurs among 1 in 25 elderly persons. I suppose then it should not be terribly surprising that similar problems can be found in care facilities—The situation indeed is tragic, but apparently not unpredictable.

It seems to me that when you have a shortage of staff, especially shortages of highly trained personnel, like physicians and nurses, you're going to have problems.

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Of course, this is of no comfort to the patients and their families who have no other alternative than to go this route.

I am hoping that today's hearing and others conducted by this committee will yield practical and effective recommendations, which might someday be translated into solutions to the problems faced by those living their advanced years in nursing home facilities. In the process, though, I believe we must keep in mind that abuses occur in some, not all, facilities. Our task is to identify the abuses and, if any way possible, alleviate them. We want to be able to assure America's citizens that age, and even institutionalization, is not something to fear. What we're doing this morning is a significant move toward that goal.

Mr. PEPPER. Thank you very much.

Mr. PEPPER. Before we start hearing our witnesses, I would like to submit the prepared statement of Congressman Synar for the hearing record. Hearing no objections, so ordered.

[The prepared statement of Mr. Synar follows:]

PREPARED STATEMENT OF REPRESENTATIVE MIKE SYNAR

First, I want to thank Chairman Pepper and his staff for bringing this very serious problem to the Subcommittee's attention.

Our elderly are being caught in a Catch-22 situation: discharged from hospitals while they are still too sick to care for themselves they may wind up in nursing homes where they are ignored and mistreated. The federal government, which pays for one-third of the total nursing home bill, has an obligation to ensure that these facilities are run in a professional manner. On the one hand, we encourage our elderly to be independent and active, but at the same time many nursing home policies stifle and prohibit this independence.

The report issued by the Subcommittee contains shocking and alarming information about the extent of the conditions in nursing homes. The most fundamental and basic rights of senior citizens are quite possibly being denied every day.

As Chairman of the Task Force on the Rural Elderly, I am particularly concerned about the incidence of abuse and neglect in nursing homes and its connection with added pressure on nursing home staffs. Rural areas already face a shortage of skilled nursing care and nursing homes. As a result many senior citizens are either being told "there's no room at the inn", or they are crowded into existing facilities. In addition, rural areas by definition are more remote which means that residents are less likely to have a family member nearby to check on them regularly.

The need for nursing homes is increasing dramatically. In fact, the Health Care Financing Administration reports a 50% increase in nursing home use in the next 50 years. Now is the time for Congress to correct this situation. I want to thank today's witnesses for appearing here today and providing the Subcommittee with useful information.

Mr. PEPPER. Now, ladies and gentlemen, you have the pleasure that you so keenly anticipated. May I present the witness that means so much to us, the Honorable Kirk Douglas.

STATEMENT OF KIRK DOUGLAS, ACTOR, LOS ANGELES, CA

Mr. DOUGLAS. Mr. Chairman, members of this committee, first, I want to thank all of you for inviting me here this morning to participate in this very important hearing.

I want to say, Senator Pepper, that as I look at you, I am reminded of the words of a poem from Robert Browning that said: "Grow old along with me, the best is yet to be, the last of life for which the first is made."

Well, we all know that for many people, the last of life is not always the best, but I believe that people, like myself and many others, who have benefited by our way of life and perhaps have done—been more fortunate than others, have an obligation to try to help others less fortunate, and for that reason, Senator Pepper, I want to join Ms. Oakar and all the other members of this commit-

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tee, I want to join your crusade in trying to eradicate this national disgrace.

You know, it is true, as you said, I am not a social philosopher, I am an actor, I create illusions, but I know the difference between illusion and reality, and the problem of elderly abuse in our land is not an illusion, it is real. It came to my attention while making a movie in which I played a man abused in a nursing home. In preparing for my role, I came across things that appalled me. I hired researchers to find out if they were true. I learned that for me abuse was make-believe, a role I could walk away from, but for more than 1 million elderly in this country, it is a hideous, inescapable reality.

I wrote the New York Times to focus attention on elderly abuse. Letters in response to my article poured in, most thanking me for talking publicly about this issue because only through awareness can we change it. But some were critical, defensive. They accused me of painting an unfair picture of nursing homes.

The reality is what one despairing health worker has stated: "The only way that patients can contribute to good enforcement in nursing homes is by dying spectacularly." That happened in Texas; 56 elderly people died in one nursing home, allegedly of neglect and mistreatment. The owners were fined $100,000. That adds up to about $2,000 a life, and the home is still open.

This year, California had to pass a law creating a new category to deal with that violation; abuse of patients resulting in death.

Some nursing homes present a pretty face to the outside world, and to official inspectors, but only during certain hours. Right here, in Washington, homes are given advance notice of inspections and the inspectors have less power to deal with violations in nursing homes than in restaurants. One home operated for 14 years without health or fire department licenses.

In an effort to combat this, the State of California made commando raid inspections, random, unannounced, outside normal working hours. Out of 10 facilities inspected this way, only 3 were in compliance with State law. The other seven received a total of 48 citations. One alone accounted for 21 violations, including sexual abuse and a patient death.

I do not want to give the impression that all nursing homes are like this. Certainly, where we filmed, caring was not an illusion; they had nothing to hide or they would not have exposed themselves to the scrutiny of a movie crew.

My own mother chose to spend the last 7 years of her life in a home for the aged where she was very happy and very well taken care of. I had the illusion that all homes were like that. I wish they were.

Mr. Chairman, as you very well know, even more elders are abused in their own homes and there are fewer laws to protect them. Only 37 States and the District of Columbia require the reporting of elder abuse, but after the abuse is reported, what happens? In Texas, last month, a man starved his mother to death. They were living in the same house. He was living in an immaculate room with his two well fed cats. He is out free because there is no law to prosecute him for the death of his mother. Oh, there are

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laws to prosecute you for not feeding a child. There are laws to prosecute you for not feeding an animal.

Right now, there is a man serving time in a Texas jail for 5½ years for not feeding his dog. The dog did not die.

This is happening in America. America, which prides itself on being a world leader in human rights. People protest against abuses of civil liberties in other countries, but what about elder abuse right here? Who takes to the streets to protest nursing homes that slip experimental drugs into patients' food without their knowledge? Who gets arrested on behalf of the 80-year-old paraplegic who is sexually abused by her son-in-law for 6 years? Who marches for the elder who has given a power of attorney to a younger relative, only to find out that they no longer own the roof over their heads? Who stands up for those whose wounds go untreated to the point where maggots, rats, and roaches feed upon the body of the living human? What we have got to find out is who protests violations of the elders' rights to respect, privacy, dignity, and freedom from intimidation.

Someone, someone must be held responsible. We must have consistent, nationwide laws for criminal prosecution of people guilty of these crimes. In 1874, the American Society for the Prevention of Cruelty to Animals, before the Supreme Court of the United States, argued that children have the same right as animals; 100 years later, the Child Abuse Prevention and Treatment Act was passed. Now, is it going to take another 100 years to get the same rights for elders?

There is nothing glamorous about growing old. Most people, certainly those with many years ahead of them, do not care because youth lives with the illusion that life is eternal and it is the young people, it is the young people especially, people in high schools and colleges, that I want to reach today because they are not aware that the nursing home population of 1.5 million will double by the end of this century and by the beginning of the next century, one of every four Americans will be over 60. You see, the problem we struggle with today is a nightmare for tomorrow. It is something that affects most strongly the young, the young people of today.

As I said, Mr. Chairman, I am an actor. I create illusions, but I know this reality. Elder abuse will end only when we have the courage to strip the facade of this hidden horror and punish those responsible.

Thank you, sir. Thank you.

Mr. PEPPER. Well, I wish every American including every Member of Congress and all the heads of the executive branch of our Government, could have heard your moving statement.

They would have been pricked in their consciences to do something, as you called upon us to do.

Let—are there any questions by the staff? I mean, by the committee? Ms. Oakar, would you like any questions?

Ms. OAKAR. Mr. Chairman, Mr. Douglas presented an outstanding statement, and we are very grateful to you, Mr. Douglas. I feel as if we can all call you Kirk because so many of us have been fans of yours for so many years.

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But, really and truly, your statement is a powerful one. You said exactly what we ought to be doing—getting to the bottom of the problem.

So, I just want to simply thank you for appearing before our committee and I know your appearance will, be a catalyst for some action.

Mr. DOUGLAS. Thank you, Ms. Oakar.

I just wanted to add one thing, that it came as a surprise to me that when I submitted my article to the New York Times, Mr. Simple, of the op-ed page, called me and he said, "Has this article ever been published?" I said, "No." He said: "Well, do you have substantiation for these facts?" I sent him three pages substantiating every point, and as a result, he published the article.

I just want to reassure the committee that in my own humble way, I have made no statement that I have not carefully checked out and substantiated.

Mr. PEPPER. Well, here today, Mr. Douglas, it will be many witnesses who, out of personal experience, will be confirming the striking things that you said, and we are sure that the American people will believe every word you said, too.

Mr. Regula, have you any questions?

Mr. REGULA. Yes; thank you, Mr. Chairman, and thank you, Mr. Douglas, for your testimony.

Obviously, you have done a lot of research or had people work on this problem.

Based on your research, what would you suggest as a solution? Should we put tougher regulations on the States, since they have primary responsibility for licensure and administration, or should there be some overriding Federal agency that polices this problem?

As you point out in your testimony, in the case of your mother, there are nursing homes that are giving excellent care, and obviously those that are not doing so well, and I would be interested in what you see as a solution to the problem.

Mr. DOUGLAS. Mr. Regula, I am certainly not an expert in this area, as most of you are, but I humbly submit that the first important fact is to bring attention, worldwide attention, on the problem that people tend to look away from.

You see, it has to deal with the perception of old people. We think of them as codgers, old geezers, senile. They have got to think of them as respected citizens, who have performed something worthwhile during their whole life.

Then, I would humbly submit that whatever we do must be consistent. I think the problem will come that if one State has one way of dealing with it and other State has another way of dealing with the problem, that will bring about confusion.

There must be some nationwide solution to deal with this terrible mess.

Mr. REGULA. So, you are really suggesting some type of a Federal agency that would have an overriding responsibility for care in the nursing homes?

Mr. DOUGLAS. Absolutely, obviously, it has to be an integrated as a nation—on a nationwide basis. We cannot have one State doing very little, and another State doing much more. That would be unfair.

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So, from that point of view, I think it should be a nationwide matter.

Mr. REGULA. Did the evidence that you adduced indicate there was a wide variance among states in the quality of care in their respective nursing homes?

Mr. DOUGLAS. Oh, there is no doubt in the research I have done. I think Utah, for example, spends the least amount of money for elderly care and elderly abuse, and there should be a much more even way of dealing with the problem.

Mr. REGULA. Thank you.

Mr. PEPPER. Thank you very much.

Mr. Sisisky.

Mr. SISISKY. Thank you, Mr. Chairman.

I was just delighted, Mr. Douglas, that you did make the differentiation between that there are some good nursing homes, that you did not paint the whole nursing home industry with one brush.

But, the other thing that impressed me is that your bringing up the point of inspections, and I know this as a fact, where they would say we will be here on September 25 at 10 a.m. and everything gets pretty.

I know when I tour, even Government facilities, they know I am coming, everything gets cleaned up and shined, and I know that some States now are not doing that. They are putting inspections and I appreciate both of those facts that you brought up.

Thank you, Mr. Chairman.

Mr. DOUGLAS. Mr. Sisisky, I, too, have been guilty of this crime. I remember when I was in the Navy, when we knew an inspection was coming, boy, my pants were pressed and my shoes were shined. But, that was not a serious crime.

When we talk about inspection of these facilities, we are talking about something that has to do with the life of these elderly people.

Mr. SISISKY. Right.

Mr. PEPPER. Ms. Schneider.

Ms. SCHNEIDER. Thank you, Mr. Chairman.

While you were speaking, Mr. Douglas, I was attempting to define some of the areas or solutions that you were recommending, and one of the areas that you touched on was the cultural changes that are needed to take place.

You said that we have a tendancy to treat old people as old geezers or whatever. So, I think that part of the solution relates not so much to this committee or any committee, but more to all of us as individuals, to teach our children, as have many different cultures, like the Japanese, that to become older is to become wiser and it is to become better.

And, so, I think that that is a role in which certainly the media has a very large responsibility.

The other thing that you mentioned, insofar as the abuse of elderly, was the inequities of judicial decisions. The gentleman who got 5 years for not feeding his dog that did not even die, and it is quite clear that we have many judges around this country, whether they be in-State judges or in higher office, that, unfortunately, are not putting forward sentences that correlate with the crimes.

So, then, we are talking about the judicial branch. Here, when we talk about the legislative branch, I think that we do have the

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opportunity to bring about some substantive changes, and one of those that is being discussed right now is setting up a National Center for Elder Abuse.

I am just wondering about the effectiveness of such a center. Granted, whenever we have any new ideas, we always have to figure out, No. 1 how much will it cost; and No. 2, will it really solve the problem or is this just a smokescreen to pretend that we are solving the problem.

So, my question is, you had mentioned that many times, abuse is reported, but it is after the fact. A clearinghouse or a national center, I do not understand how it would have any preventive elements to it, and have you thought much about the idea of setting up a National Center for Elder Abuse and in what way it might be able to not just bring the issue to the attention of the American people, but how might it really end up preventing such problems in the future?

Mr. DOUGLAS. Ms. Schneider, before we develop national centers that deal with these abuses, I think we have to deal with what you said in your first part of your statement, perception of older people.

For example, in China, if anyone is guilty of mistreating the elderly, they are executed. As a matter of fact, the neighbors, if they are aware of elderly abuse and do nothing about it, they are executed.

I am not suggesting that we take such extreme measures, but I do think that young people, like Senator Pepper and myself, should change the perception of what old people are, and what they have been, and realize the inequity that is being caused, and by first getting about that perception, we can form a center that can be able to evaluate these things.

We have not yet got to the point where people will really look at the importance of this problem, as you members of this committee have done.

Ms. SCHNEIDER. OK.

Mr. PEPPER. May I add, if the lady will allow me to interrupt, we are going to offer at this hearing what we call a bill of rights for the elderly in institutions, in which we will lay down what we conceive to be their rights in these institutions. This document will prescribe standards of care, which we hope the nursing homes will be required to observe, and then, you remember, the subject of regulation of nursing homes comes under the jurisdiction of the Department of Health and Human Services.

I am sure we will find that Mrs. Heckler, who is the distinguished Secretary of that agency, will be sympathetic. I think her representative will be among the witnesses whom we will hear today.

So, we are going to try to prescribe standards and then move toward the implementation of those through congressional activities.

Thank you very much.

Mr. Lightfoot.

Mr. LIGHTFOOT. Thank you, Mr. Chairman.

Mr. Douglas, going back to Mr. Regula's question, you had mentioned in your testimony that there were good nursing homes and we are aware that there are.

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In your opinion, why are those homes as they are as opposed to those that are not? Maybe we could learn something from the experiences of the people who do run good nursing homes? Are they because of regulations, the attitudes of people who own it, or where is the key or is there a key?

Mr. DOUGLAS. I think the answer is in one simple word: "greed." Obviously, for the most part, unless they are a charitable institution, the nursing home is a business that must make money.

I am not against the free enterprise of businesses making money, but at what price, and I think that is where you keep running into this problem in elderly abuse. Where, in order to make more money, they cut down staff, cut down attention, cut down—I mean, you and Mr. Senator Pepper's report, I have seen so many instances of neglect, all caused by cutting down staffs, which has to do with trying to increase the profits.

Mr. LIGHTFOOT. Do you think that more regulation by the State would be, such as you mentioned in your testimony, the raids that California made, a good way to detect this type of thing?

Mr. DOUGLAS. Well, as I said before, I am not an expert in these matters. All it seems to me is there has to be a consistent form of dealing with these problems on a State level and on a national level.

Mr. LIGHTFOOT. Thank you, Mr. Douglas.

Thank you, Mr. Chairman.

Mr. PEPPER. Mr. Swindall.

Mr. SWINDALL. Yes, Mr. Chairman.

Mr. Douglas, first of all, I want to commend you for your testimony, and I certainly concur with everything that you said.

But, I would like to ask you a more general question, and that is, do you not think that at least in part the problem of the ever-increasing incidence of abuse of our Nation's elderly might well be linked to our society's devaluing of human life in general, which has resulted in the wake of the historic *Wade* v. *Roe* decision, which basically legalized abortion in this country?

Mr. DOUGLAS. I am not going to get involved in that.

Everybody has their own personal evaluations. Abortion is an entirely different issue that right now is a very hot issue. People are very strongly convinced on both sides, but one issue that I think that can be a unanimity of opinion has to do with elderly abuse.

Mr. SWINDALL. But, is there not a common linkage between the two issues, and that is the value which this society places on human life?

Mr. DOUGLAS. I do not see that commonly.

Mr. SWINDALL. Thank you.

I yield back.

Mr. PEPPER. Mr. Ridge.

Mr. RIDGE. I want to join my colleagues in thanking you for your thoughtful and much needed, in many ways, dramatic presentation, explaining for us and giving the benefit of your experience, the plight of the elderly.

I think we all have in our respective congressional districts many nursing homes to whom we can point proudly. They recognize the quality of the human life that you value and we all value. They provide the staff, the aid, the treatment, that we all want to be pro-

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vided, and we can also turn to those nursing homes that cause us, as legislators, some problems.

So, I think we are all in agreement that your push, drive, the emphasis on a national commitment, indeed, is a good one. I am not sure that you can legislate specifically the kind of commitment, I think, you need from individual family members and friends who have to assist the level of government judicial authorities, law enforcement authorities, in identifying the sources of abuse.

Clearly, there are some family members that, over the years, for a variety of reasons, some we may understand, some do not pay as much attention as they should, to their mom and dad, to their parents, to those responsible for giving them a better way of life, and I am not sure we will ever be able to legislate that.

But, I wondered if you might comment, based on your experience and your research, as to the reporting mechanisms that are the sources of information that you are able to uncover? Was it strictly family that brought these situations to the fore, to the law enforcement agency? Were they aides? Were they in the institutions that brought it to the fore?

And, would you have any reccmmendations? I know your presence here and your testimony and the increased level of awareness may make people out there more willing to step forward, and complain, and point out these problems.

But, in your experience, was there—what were the reporting mechanisms used, and do you have any thoughts about that? How we can encourage more people to report those abuses because, indeed, I think most district attorneys, most States have laws that I think you could use to enforce.

Mr. DOUGLAS. Well, you bring up a very important area because I think it is important that we commend nursing home functions with compassion just as we condemn nursing homes that do not.

But, I think the awareness of this problem, the area where it is most neglected, is with the young people. I would like to see high schools, universities, have subjects that deal with this because it is hard, when you are young, to think that you will ever be old, that you might be faced with this problem, and as I said in my report before this committee, the young people of today are the ones who are going to suffer the most.

So, really, I think the most important aspect is not to bring this so much to the attention of the elderly, who are very well aware of what these problems are, but to bring it to the attention of the young people of today.

Mr. RIDGE. I appreciate that, Mr. Douglas.

Yield back the balance of my time.

Thank you, Mr. Chairman.

Mr. PEPPER. May I interrupt? I think you are so wise, Mr. Douglas, in taking your great appeal to the younger people of the country, and I believe they are beginning to see what you are talking about and to respond.

If I may mention a personal experience that I had, a few evenings ago, some of my friends were giving me a birthday dinner at one of the restaurants in the city. A lady came up and said: "There's a group of people downstairs on the first floor who want to give you a plaque for what you are trying to do for the elderly."

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I just naturally assumed it was a group of older people who were there to make that presentation. So, with the permission of my host, Ms. Oakar and I went down to greet the people and receive the award. Whom did we meet? About 20 young people. There was not a one of them over 35 years of age, and, yet, they were there to talk about the problems of the elderly. They all seemed well dressed, and they looked like they were fine, young men and women of our community.

So, I believe with people like you calling upon them to respond, they are already getting the message and are beginning to respond to such appeal.

Ms. OAKAR. Mr. Chairman, would you yield for 1 second?

Mr. PEPPER. Yes.

Ms. OAKAR. You mentioned that young people have a need to hear about the problem. That is what a national clearinghouse would do; it would disseminate information and conduct research on the causes of and treatments for elder abuse.

There are a lot of people who abuse their parents. Many have problems of their own like those who lose their jobs and have the pressures of not having social services.

We have a National Center for Child Abuse that is making the public much more aware of the problem and trying to find solutions.

But, we do not look at elder abuse in a comprehensive way. That is what a national clearinghouse would do.

Thank you.

Mr. PEPPER. Thank you.

Mr. Boehlert.

Mr. BOEHLERT. Thank you very much, Mr. Chairman.

I bring you greetings from Amsterdam. Beautiful upstate New York. We are all proud of you.

Mr. Douglas, I hope you will continue your fine work. We have before us, as we deal with these very sensitive subject, a very impressive list of people who are expert in the field, and not to denigrate in any way, shape, or manner your fine testimony, but you come forward as a concerned citizen, rather than an expert, and because of your celebrity status, we have all these cameras and all this attention on this hearing. What you are saying today is the message that the American people should hear. I hope that you will continue to speak out.

You should go forward and do more fine missionary work like this so that everyone in this country can be sensitized to the very important issue with which we are dealing.

I just—I could not be happier or prouder of a fellow American than I am with you today because you have done something very important. Despite all the charm of our distinguished chairman and despite the very important nature of the subject matter we deal with, quite frequently, we have hearings before empty rooms, cameras are not here. We all love cameras. We know that, but reporters do not cover our deliberations, but because you are here and you are who you are, there is a great deal of attention, and I want to publicly applaud you.

Keep it up and I would like to work with you if you intend to keep it up.

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Mr. DOUGLAS. Thank you.

Mr. WORTLEY. I want to thank you, Mr. Douglas. I think you are a greater star at this stage of your life than you ever were before, that you would focus attention on this national problem.

On behalf of the Congress of the United States and the elderly, who have been abused, I would like to thank you.

Mr. DOUGLAS. Thank you.

Mr. WORTLEY. I yield back the balance of my time.

Ms. MEYERS. Thank you.

Mr. Douglas, I do think the States have an enormous role to play in this. I was in our State legislature for 12 years, and I authored an Elderly Abuse and Neglect Act, which carried heavy penalties for those who abused elderly, either in institutions or outside of institutions, and called for mandatory reporting of anyone who saw an incidence that they suspected to be of child abuse—adult abuse and neglect.

We called for improved conditions in nursing homes with prescribed numbers of hours of training and testing before an aide could give any hands-on care to the elderly in a nursing home.

We formed a relationship at the State level with the local health department so there could be surprise visits in nursing homes because, frequently in a small town, if the State inspector is in town, everybody knows it before they get there, and, so, we did form this relationship so there could be surprise visits and middle-of-the-night visits, and that sort of thing, and we gave the State the ability to take over that nursing home if any of the deficiencies in that nursing home were not corrected.

Now, after that long lot of comment, I will say that this was all possible, although I introduced most of that legislation, it would not have passed without citizen concern, and, so, I am very grateful for the fact that you are here today.

It takes groups of people who are organized, who go to the State legislatures to testify, who drop in on nursing homes in their local communities, who just frankly raise a lot of hell if things are not right, and legislators alone cannot do that. Concerned citizens can.

I think that is what you are doing here today, and I am very pleased.

Mr. DOUGLAS. Well, I would like to add that I think that these commando raids will become less necessary when people are punished for crimes that are committed. If people continue to act in a way with impunity, nothing much is going to be accomplished.

There has to be a system devised, and if a person is guilty of a crime, he should be punished. That is our way of life.

Mr. PEPPER. Mr. Douglas, before you leave, with our profound gratitude for your coming here today, I would just like you to know that this committee on a bipartisan basis proposes to offer what I have referred to as the bill of rights of the elderly in these institutions. Let me just read it.

They are listed up there on the wall.

First, the right to complain and seek redress of grievance.

Second, the right to make basic personal choices.

Third, the right to privacy.

Fourth, the right to maintain personal possessions with security.

Fifth, the right to freedom from verbal abuse.

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Sixth, the right to adequate and appropriate medical and nursing care.

Seventh, the right to freedom of movement.

Eighth, the right to a clean and safe living environment.

Ninth, the right to freedom of speech, assembly, and religion.

Tenth, the right to freedom from physical or sexual abuse.

Those make up the 10 proposed planks in the bill of rights that we have proposed to offer to the Honorable Secretary of Health and Human Services for administrative action and to the Congress, and we would hope that that bill of rights or something similar would hang in every nursing home in America, so that people could read on the walls what their rights are and could tell those who would question those rights that they have those rights to enjoy. Then there would also be redress available when those rights were not protected on behalf of those people.

Well, Mr. Douglas, we are profoundly grateful to you for coming here today. You made an immeasureable impact upon this subject and upon the hearts of our people, and on behalf of all those who may live a little better life toward the end of the way, I want to thank you.

Now, we will take a brief recess and then we will resume the testimony according to our schedule.

[Brief recess.]

Mr. PEPPER. We will now hear from our first panel.

Mr. Joseph Valley, Jr., son of former nursing home resident, Houston, TX. Please proceed.

STATEMENT OF JOSEPH VALLEY, JR., SON OF FORMER NURSING HOME RESIDENT, HOUSTON, TX

Mr. VALLEY. Mr. Chairman, members of the committee.

My name is Joseph Valley Jr., and I am from Houston, TX. I want to thank you for giving me the opportunity to testify before you this morning. I came here to tell you first hand of some problems with one nursing home in Houston, the Blalock North Nursing Home owned by ARA Services, Inc.

It is one thing to read accounts of nursing home horror stories in the paper, or to watch it on TV. It is something else again when it is your close relative—in my case, my father—who suffers the neglect and abuse.

Our family did not want to put dad in a nursing home, but the doctors at the veterans' hospital said he needed skilled care. We were told that this was the only home in our area that could give that kind of care and which had room for my father. When my mother and I visited the home, the staff painted a very rosy picture. They said dad would receive constant attention and would be turned over in his bed at least twice a day.

The first couple of weeks, things seemed to be going ok. The next 2 weeks things started to really get bad. We made numerous compliants to the nursing home administrator. Nothing seemed to be happening despite our continuing to complain. One administrator finally told us that they were going to investigate, so "give us a chance; we are going to investigate."

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I did not want to take a chance with my daddy. I wanted them to try to help me.

Every day I went to see my daddy, it was as if he had not eaten in days and days.

We took it upon ourselves to bring some food from home, my wife and my mother. We fixed the food. We took it to him, and we fed him, and he was always starving—I'm talking about from the first day to the next day, as if they had not paid any attention to him.

And every day I came to see him, I paid attention to the bedsores, the gangrene, and as if they had never paid any attention to him. They did not change the catheter, and it smelled.

This particular place smelled horrible. I heard other patients moan, and groan, and noted strong signs of physical abuse, and it was atrocious.

On another occasion, I came to see him. He was sitting in the wheelchair, just limp, with nothing on but a hospital gown—no underwear or nothing—a partial hospital gown, in a limp position, just sitting there. He was starving, starving to death.

What I am trying to mention to you all this morning is that something needs to be done. I don't know what, but when my daddy had to die the way he did, he didn't go in there like that.

When I weigh the type of life he lived and the way he lived as opposed to the way he died, there is no comparison.

As my daddy stayed longer it was hard just to see him there, laying there, not helping himself; and I was wondering what goes on in the minds of people in this world who would let a human being suffer and die like that.

My daddy told me he wanted to go home. And we took him there in good faith with the intentions that it would be temporary, and that he would be observed, and treated properly. They didn't even come close.

So, I'm saying to you this morning, that there has got to be something wrong, somewhere, for human beings in this day and age to let a person die like that.

The nursing home killed my daddy. It killed him. I'm not saying with a knife or with a gun. I never saw any physical abuse, but if you weigh the fact that they totally neglected him, they murdered him.

And if just one doctor or one nurse had seen my daddy just for 1 day—just for 1 day—I want to think they would have done something.

If they saw him and didn't do anything about it, then that is murder.

So, I want to say that I don't know what can be done, but the 38 days that I visited my daddy—and he died the way he did—I think about all the other people that are in these nursing homes who may not have had as many visitors as my daddy did—and I did everything I could about keeping him alive. And they killed him.

I just want to say, you read about things; you hear about things, but until you know about them—I know; I saw it; I saw it.

The day before we took my daddy to the Veterans Hospital—that's where he passed; he left the nursing home on the second, I

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told my mother and my brother: "I'm sure my daddy's going to pass, because he's not going to be here tomorrow."

I was calling him—he pushed away the food, pushed it away.

For 40 years—for 40 years, I never saw my daddy like that. He was one heck of a man!

I beg you, Mr. Chairman, members of the committee, and anybody that can put a stop to it—let's do it right now, because they killed my daddy.

Thank you very kindly.

Mr. PEPPER. Thank you, Mr. Valley.

Our next witness will be Ms. Ruby Seidler.

Ms. Seidler.

STATEMENT OF RUBY SEIDLER, 79-YEAR-OLD NURSING HOME RESIDENT, NEW YORK, NY

Ms. SEIDLER. Congressman Pepper, I am very grateful—can you hear me now?

Mr. PEPPER. Yes, indeed. That is good. We live by microphones in these days, Ms. Seidler. Go right ahead.

Ms. SEIDLER. All right. Congressman Pepper, I wish to wholeheartedly thank you for allowing me to come today to testify on the residents' perspective in the nursing homes.

My name is Ruby Seidler. I am president of the Coalition for Institutionalized Aged, usually called CIAD, and we are also members of the National Citizens Coalition for Nursing Home Reform, and we are very grateful to Alma, and Barbara, and everyone else there for the help that they have given us in trying to make life in the home very much better.

As I said, my name is Ruby Seidler and for the past 7 years I have been a resident in two different homes. I left the first home because the State had given it over to a man who should never have been allowed to even enter a home.

The first morning after he occupied the place, we woke to find the place filled with armed guards with a hose extending into the street against anyone who might be passing, and that at least nine-tenths of the staff of that home had not been allowed to even enter to pick up their personal possessions. All new people.

You can quite understand the chaos, the trauma, and the feeling of most of these people who had lost all their friends and everybody who had taken care of them over the years, and, so, I went about trying to find a new home and finally did locate.

Now, I must say to you that a home is just not an institution, unless you, yourself, have lived in the home, you cannot really appreciate the feeling that you have when you live in a home. It should be a home in every aspect of life. It should be a caring place, where everybody who deals with you is a friend, not just an inanimate object, to come around to sort of take care of you, if you can call what they do taking care of you.

It should give dignity to human beings. I will say that really what I am saying is reiterating what Congressman Pepper and Mr. Douglas said.

However, I am doing this from the viewpoint of she who lived it. We should preserve and enhance the quality of living, not only life,

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but living. It should give the last years tranquility and peace of mind, but do they?

New York State has passed laws implementing, presumedly, residents' rights. They are on paper, it is true, but are they carried through? That is another question.

Many people, including the surveyors, when touring a home, really see only the outward appearance of the home, the showplace, that is what they are shown, and that is what they see, and that is what their impression is, and that is what they take with them. They do not really see the day-to-day living of the residents.

Do they really try to find out whether the administrator and the staff are warm and caring? No; I doubt whether they spend very much time with the administrator. Probably no more than the administrator spends with the residents.

This is not true in all homes, but it is true in many of the homes when I speak to the people. Many people do not even know the name of their administrator because he is never visible, and that really goes down to the entire staff.

If the administrator does not care, does not show himself, then the staff works along the same lines.

Now, does the staff really perform their duties only because it is their job? They do not seem to see that they are human beings and that it must be a sensitive meeting with the people. There are different kinds of meeting with people. I have often said that I could meet two people in the street or two people in the home, both smile and say hello; one of them chills my heart, and one warms my heart, and that is the difference between what a person on the staff should feel.

Another thing that they have is that there is a constant turnover on the staff, particularly recently. We are a--well, we are really starting a case mix, and I tell you it is an abomination. I am sure that none of you whose minds are still working would like to live constantly with people who are Alzheimer's patients, people who are very sick, people who do not know whether they should get dressed to come out in the hall or undressed, who do not know what they are eating, and, yet, you are spending the rest of your life there if you cannot run away the way I am running away.

So, we must try to see that this case mix thing is better taken care of because it is going to deteriorate rather than enhance the living of the people.

I have written down here very shortly a few things that we may discuss about the different kinds of treatments in the home.

No. 1. The staff marches into the room uninvited and unannounced, often without knocking or waiting for you to answer the knock. Most often, their intrusion is unnecessary and the reason they give is just a shrug of the shoulders, ch, that is my job. They have no reason for coming there.

No. 2. Theft is reported very often, but the culprit is rarely apprehended, and the item rarely returned.

No. 3. Laundry may take days or weeks to be returned, and often articles are never returned. Staff often uses the clothing of one patient or another patient without permission, and the original owner never knows what happened to his clothing.

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No. 4. Verbal abuse and harassment are common and because of fear of retaliation, neither the residents nor their families ever complain. They are afraid and they have a right to be because there have been retaliation against residents and the relatives in many of those cases.

No. 5. Patients are constantly being told that they are a nuisance, a pest. They are rudely shoved into their clothes. They are rarely bothered to change the dresses daily or to give them a choice of clothing. They are pushed and insulted.

I have heard that from residents from many, many of the homes that we visit.

No. 6. Call bell. Yes, every home has a call bell, but when are they answered? If a patient calls, in order to be taken to the bathroom, sometimes he waits 15 to 20 minutes and more. Sometimes he has to ring the bell three or four times, and if he is one of those pests, he can wait even a longer period of time, and the same length of time is taken to return him to his room.

Also, for the convenience of the staff, many people who are not really incontinent are placed in diapers in the night, so that they will not bother to ring the bell and bother the staff to come to them. That is a very humiliating experience.

One man in a wheelchair was pushed out of the elevator with such force that he bounced off the opposite wall. No action was taken in that matter.

A friend of mine was told by a home psychiatrist to go to another home if she was not satisfied with the one that she was living in.

Since you must use the home's doctor, misdiagnosis is frequent. Also, medical treatment and doctor attitudes are very deplorable.

A friend told me that upon complaining bitterly of pain, she was told to wait until after the weekend to go to the hospital because, after all, the pain cannot be that bad. She called the police because the pain was that bad, and he sent an ambulance. She was taken to the hospital, and her gall bladder was removed. They found it filled with stones.

The home was rather angry about the situation and told her to go to another home, probably for disobeying them or for putting them in a poor light. However, she is still in the same home.

Some time ago, after a gall bladder and hernia operation, my husband was brought back to the home where we reside and placed in skilled nursing so that they could rehabilitate him. Well, the rehabilitation did not take place. I visit him twice a day and found him always either lying in bed with a diaper on or sitting in a chair with a diaper on.

Well, I said to myself, this just cannot go on. So, I brought a walker and a cane over to his building and each day, twice a day, I made him walk up and down the corridor; first with the wheelchair, and then with the cane. Finally, after a good deal of argument because they said I simply could not take care of him, they allowed him to come back to the health-related section with me.

Within 1 week, he was living like a human being. He was walking around. We had discarded the diaper, and he was again a man.

Now, where was the therapy that was needed? Our home does have a therapy department, but with over 500 patients, they cannot give any patient more than 10 to 15 minutes every 2 or 3

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times a week. That is not sufficient. They need more. They need a great deal more in order to take care of the patients.

Now, suppose I had not been there. What would have happened to my husband? What about the people who have no relatives that come and take care of them? Life is really at the mercy of the staff. People are afraid to complain and outright neglect and insensitivity causes depression and desire for death.

The constant turnover of staff is confusing. The staff is confused, the residents are confused. Every second or third day, there is another aide on the floor. They do not know the patients. The patients do not know them. They become a little irritated and the patients become more confused.

There should be something, and they claim in theory rotation is a good idea, so that in case an aide does not show up, they have someone else to take over, but they should have the same people all the time, not different people, strangers coming around, strangers in the land not of paradise.

My last illustration is about a knowledgeable woman who is frustrated because it was difficult to communicate with her doctor. Her high cholesterol had been reduced years ago and after a blood test, she asked what the count was. It had risen quite high. When she questioned the doctor as to why she had not been told, he replied, oh, cholesterol is not important in the older person. That is what he says.

This woman, who was I, it bothered me so much how little the respect the doctor showed for me. Health conditions are very rarely discussed with the patients, even if you question them, you have to be an aggressive type of person like the one sitting before you before you really get an answer from any of them, and I do not think they like it.

Health charts are also forbidden to the patients. I do not know why. I do not know why I cannot know what they are saying about me. They could say anything they want, and I do not think that is quite fair.

As I have considered the conditions that I have discussed today, I ask myself, does entering a home require the sacrifice of basic rights? Is expecting proper medical care and human dignity too unrealistic? Must invasion of privacy, insensitivity, neglect, and dehumanizing attitudes continue?

I pray that the answer is no. I have given a modified version of life in a home. In reality, it usually is not truly living, it is merely existing. It is like living in a vacuum. At best, the atmosphere is polite, impersonal, and mostly uncaring. There is very little warmth or emotion or tenderness. At worse, it is an existing nightmare.

We cannot change human nature. We cannot teach that working in a home is not just a job, that only requires knowledge and skill. It is a caring position, caring for human beings who need warmth and friendliness, not just a cold smile and greeting, but a smile that gives warmth.

We must also beware of covert abuse. I will honestly say I have never been abused, but I have been sort of chilled on occasion. So, let us say not only is covert abuse not to be expected, but also overt abuse.

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And, my last point to ponder is visits and studies to homes in Western Europe show that they are far superior to those in our great big United States of America. I have spoken to people who have been to Finland, to Germany, West Germany, to the Scandinavian Peninsula, and they have told me that the administrators are horrified at some of the conditions in the great big United States homes.

They were horrified to think that two strangers could be put together in one room and expected to exist for the rest of their lives happily. It is utterly ridiculous and so are many of the other things.

But, just making rules is not enough. The State government, the Federal Government, could make a lot of rules, but if they are not implemented, what is the good? And, I do believe that our new idea of case mix and our rights are going to make life a great deal more deteriorating rather than enhancing the quality of life in our country.

Thank you.

Mr. PEPPER. Thank you, Ms. Seidler.

I will have some questions for you in a little bit.

Next, we have Ms. Janet Tulloch.

STATEMENT OF JANET TULLOCH, 20-YEAR NURSING HOME RESIDENT, WASHINGTON, DC

Ms. TULLOCH. Thank you, Mr. Pepper.

Rather than assuming the role of indignant consumer, I chose to discuss this morning some reasons why health care systems have difficulty implementing residents' rights. We all know that an increase in the older population has spawned an unwieldly profit-making industry of nursing homes. We also know that the feminist movement has caused a proliferation of superb priests and politicians, while creating a drastic shortage of nurses and teachers.

Residents' rights have become an inadequate idealism because nursing homes are also an inadequate idealism. Although regulatory agencies have tried to prevent traditional forms of abuse and negligence, courtesy and dignity cannot be legislated.

When I insist that staff persons knock before entering my room, the usual answer is why, and I know of no response to this.

A venerable gentleman and honored scholar struggles in a wheelchair tied to a handrail with a sheet. Medication might also be used to restrain such residents from wandering into other rooms, taking things, or lying in another resident's bed.

Violations of rights are subtle and ambiguous. Withdrawing petty cash from a facility's financial keeping makes staff both banker and parent. Being warned to be careful where you keep it is a legitimate concern about theft. It is also an affront to any resident's dignity. Do automatic tellers give similar messages by recording? Shutting out such admonitions takes much energy to maintain a self-dignity. Here I covered three rights, the holding and dispensing of moneys, freedom from theft, and the issue of respect and dignity.

The right to a safe, clean environment also becomes contradictory during periodic roach exterminations. When such procedures re-

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quire putting all my possessions in plastic bags and vacating my room for 4 hours, how much dignity, privacy, and personal space has been violated? If such stringent measures are necessary, can I refuse the use of toxic chemicals in my room? How safe is the environment when I return to my disorganized closet and topsy-turvy desk drawers? This is a situation where one resident right contradicts three or four others. Such dichotomies within the system confuse and ridicule the ultimate concern, the resident.

Such discrepancies make comprehensive effort for more appropriate implementation very difficult. A protesting resident fears retaliation, perhaps in the form of less physical care. The less vocal sink into morose lethargy, depression, and subtle forms of debilitation. Our vulnerability is physically and psychologically devastating. Much education and research needs to go into developing a more feasible implementation of residents' rights.

Thank you.

Mr. PEPPER. Thank you, Ms. Tulloch.

You have given a very scholarly presentation. Thank you.

Next is the nursing home aide whom you know as X. Ms. X, we will be pleased to hear you.

STATEMENT OF NURSING HOME AIDE X, WASHINGTON, DC

Ms. X. Mr. Chairman, members of the committee, in 1981, I was hired as a nurse's aide at a high-skilled nursing home facility in central Ohio. Now, how did it happen that I, with no experience, no skills, no medical training of any kind, was hired at a high-skilled facility, one designed to handle delicate and seriously ill patients? I needed a summer job, and, so, when I walked in and asked if they would hire me, the head nurse said, when can you start.

That summer opened my eyes to a lot of things, including the inadvertent, but nonetheless, subhuman way people were treated in the nursing home where I worked. We nurses' aides were simply not trained to deal with high-skill facility patients, and our elderly that we worked with became the victims of our inexperience.

Now, I was unique among the aides where I worked because I had been to college. Many of them had not finished high school. But, after that, we were pretty similar: like me, most of them had needed a job, any job, and found being a nurse's aide a fast way to get hired. None of us had been to any kind of training program at that nursing home before we started to work there. We got our experience on the job, at the expense of the elderly we worked with, and that is significant because we had almost all of the direct personal contact with the patients. In fact, during the 3 months that I worked there, I never saw a doctor on the premises, and there was approximately one RN per about each 60 patients. Now, every day, my job included things like cleaning, feeding, dressing, turning of approximately 40 patients. In fact, I heard things in Senator Pepper's testimony this morning that I was not allowed to be doing because a nurse should be doing that, that I did every day. I did not even know that till this morning. Nobody taught me how to take a pulse, but I recorded it on medical charts every day.

There was one woman who was the victim of a particularly bad error in my trial and error learning. She screamed in pain each

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time we turned her. I asked, "Do we have to turn her?" But, yes, we did. So, until she was taken half-conscious to the hospital, we turned Eliza while she screamed in pain. What we did not know was that, thanks to her bone cancer, every time we turned in, we were literally breaking bones all over her body. We did not know that. Well, why not? Why was not a high-skilled facility that is supposediy equipped to handle delicate patients equipped with the knowledge that turning a bone cancer patient breaks bones? I wish I knew.

Not every day as a nurse's aide is that dramatic, though. The first things that seemed wrong were the little things, like freedom of choice. You could choose what you wanted to wear, but you could only keep a few of your own clothes because of the lack of space and almost all of the patients wore hospital gowns because nurse's aides complaints about the difficulty of dressing someone in their own clothes. Many, many personal items went to the laundry and never came back.

No choice at all was involved in meal fare, and there was little choice in bedtime or roommate. I remember Wilma, who was paralyzed by a stroke, but otherwise pretty healthy, who had seen a series of roommates die of painful, terminal illness in the bed next to hers. Now, think about that. It is bad enough knowing that you are probably going to die in a nursing home, but what about the psychological damage of watching people screaming of terminal illness and dying in the bed beside you, patient after patient?

My guess is, though, that if you walked into the nursing home tomorrow, your biggest shock would probably be what mine was: that is the inhumane treatment and even less so, the absolute insensitivity to the patient as a person. I saw active, vital members of my community reduced to pets. For 17-year-old nurse's aides to boss around, and the person, anxious to avoid attention in his living environment, tries to cooperate.

In their hurry, the aides would constantly resort to dog talk when they addressed an elderly person. Come, Vern, sit, Myrtle. Stay, eat." Now, do you talk to your mother that way? Even more demoralizing was the daily third-person conversation. What I mean by that is when you speak to a person in the room as though they are not there. When I was introduced to Myrtle, the aide said. "That is Myrtle. She is confused and she wets herself." Now, is that how you would introduce your mother?

All of this says nothing of the inherent loneliness of living in a nursing home in the first place. Most, if not many, of these patients, we nurse's aides became surrogate friends and family, not just caretakers.

I remember coming home—coming back to work after lunch one day, late in the summer, and I was called into the nurse's office, where I was confronted by every aide on my shift. I was evidently in some very hot water.

The charge, the head nurse simply told me you are spending too much time with the patients. Now, I would like to be able to say that these problems never existed in the good nursing homes. They are out there, but I cannot say that those nursing homes are exempt.

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The nursing home I worked in was a good nursing home. It was clean, well kept, and the people who worked there are good people, just doing their job. But, unfortunately, even in good nursing homes that are understaffed with underpaid and undertrained employees, abuse is inevitable.

Right now, I am a divinity student at Wesley Theological Seminary. Why am I testifying? Because I was lucky. I could walk out of that nursing home in August 1981 and never return. I never have, and I am not very proud of that.

But, every other nurse's aide I know needs her $3.35 an hour too desperately to report or even think about reporting what is to her all in a day's work. You know, you get to the point where you do not see anything wrong with turning a patient too quickly or with tieing someone to their bed. You are so tired.

I hope that my being here this morning can ultimately improve conditions, both for nurse's aides and for the patients. If this committee can protect the rights of the nursing home patients, aides who are more qualified than me will be hired. Rights will be upheld and human decency restored.

We all have a right to grow old with grace, do we not?

[The prepared statement of Ms. X follows:]

PREPARED STATEMENT OF NURSES AIDE X

Mr. Chairman, members of the committee, in 1981 I was hired as a nurse's aide at a high skill nursing home facility in Central Ohio. How did it happen that I, with no experience, no training, no medical skills of any kind was hired at a high skill facility—a facility for residents with serious medical conditions? I needed a summer job, and when I walked in and asked if they'd hire me, the head nurse simply said: "When can you start?"

That summer opened my eyes to a lot of things, including the inadvertent, but nonetheless sub-human way people were treated in the nursing home where I worked. We nurse's aides were simply not trained to handle high-skill patients, and the elderly in the home became the victims of our inexperience. Put simply, in the summer I worked there I saw elderly residents stripped of both human rights and human decency.

I was unique among the aides where I worked because I had been to college; many of them hadn't finished high school. But after that, we were pretty similar. Like me, most of the aides had needed a job—any job—and found being a nurse's aide a fast way to get hired. None of us had been through any "training" program at the nursing home before we started to work there; we got our experience on-the-job, often at the patient's expense. And that's significant, since we had virtually all the personal contact with the patients. In the three months that I worked there, I never saw a doctor on the promises, and there was only one R.N. per approximately 60 patients. Except for administering medicine, the nurses didn't really interract with the patients; that was our area. Each day I was responsible for cleaning, feeding, dressing and turning about 40 people, and I learned my "trade" by trial-and-error. Sometimes the errors were grave. There was one woman who screamed in pain each time we turned her. "Do I have to turn her?" I asked the nurse. Yes, she said. So—until she was taken half-conscious to the hospital—we turned Eliza while she screamed in pain. What we didn't know was that, thanks to her bone cancer, with every turn we were literally breaking bones all over her body. Why didn't we know? Why wasn't a high-skill facility, supposedly equipped to handle delicate patients, equipped with the knowledge that turning a bone-cancer patient breaks bones? I wish I knew the answer to that.

Not every day as a nurse's aide is dramatic, though. The first things that seemed wrong were the simple things, basic human rights, like your freedom of choice. The residents could only keep a handful of their own clothes due to lack of space, and almost all of our patients wore hospital gowns because nurse's aides complained about the difficulty of dressing people in their own clothes. Many, many personal items went to the laundry and never came back.

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No choice at all was involved in meal fare, and there was little choice in bedtime or roommates. Sane patients were paired with "confused" and sometimes violent residents. If you were lucky enough to have a family who would complain about a bad rooming situation, then a switch could be made. I remember Wilma, paralyzed by a stroke but otherwise healthy, who had seen several consecutive roommates die of terminal illness in the bed next to hers. It's bad enough knowing that you're probably going to die in a nursing home, but what about the psychological damage of watching several people die in your room? I watched the death of one of Wilma's roommates, who—for the first time in weeks—suddenly stopped screaming and closed her eyes. The moment was a visible relief—for both of them.

My guess is, though, that if you walked into a nursing home tomorrow, your biggest shock would be what mine was—the absolute insensitivity toward the patient as a person. I saw active, vital members of my community reduced to "pets" for 17-year-old nurse's aides to boss around. And the early person—anxious to reduce tension in his or her living environment—generally tried to obey their commands. Hurried aids, not thinking, constantly resorted to "dog talk" when addressing an elderly patient. "Come, Vern. Sit, Myrtle. Stay. Eat." Is that how you talk to your mother? Worse yet were the daily, demoralizing "third person" conversations—talking about a person to his face as though he wasn't there. When I was introduced to Myrtle, the aid looked at her and said, "That's Myrtle. She's confused and she wets herself." Is that how you'd like your mother introduced?

And all of this says nothing of the inherent loneliness of living in a nursing home. For many, if not most, of our patients, we nurse's aids became surrogate friends and family, not just caretakers. I came back from lunch one day late in the summer to find my self confronted by every aid on my shift. I was evidently in some very hot water. The charge? The head nurse told me: "You are spending too much time with the patients." I asked what it was that I was not getting done as a result. Nothing. Just too much time with the patients.

I'd like to say that these problems don't exist in "good" nursing homes—but I can't. The nursing home where I worked was a "good" nursing home, clean, well-kept, with good people working there who were just "doing their jobs." Unfortunately, even in good nursing homes that are understaffed, with underpaid and undertrained employees, abuse is inevitable. Right now I'm a divinity student at Wesley Theological Seminary. Why am I testifying? Because I was lucky—I could leave at the end of the summer and go back to school. But every other nurse's aide I know needs her 3 dollars and 35 cents an hour too badly to report—or to even think about reporting—what to her is all in a day's work. You get to the point where you don't even see anything wrong with turning a patient too quickly, or tying someone to his bed, you're so tired. Fortunately, my job is not jeopardized if I tell you what I saw. I was free to walk out of that nursing home in 1981 and never return. I never have. And I'm not very proud of that.

Hopefully my being here today will help improve conditions for both nurse's aids and patients alike. If this committee will defend the rights of people in nursing homes, aides more qualified than me will be hired, rights will be guarded, and human decency will be upheld. We all have a right to grow old with grace. Don't we?

Mr. PEPPER. Our next witness is Dr. Y, a former corporate nursing home official.

Dr. Y, we appreciate hearing from you.

STATEMENT OF DR. Y, FORMER CORPORATE NURSING HOME OFFICIAL

Dr. Y. Mr. Chairman and members of the subcommittee, I am here today as a willing witness who, unfortunately, for my protection, must not divulge my name or the name of the company I am here to discuss.

I am from Houston. As a former corporate official for one of the largest nursing home chains in this country, I am submitting information to you today which I hope will strengthen regulations and improve care for our Nation's elders.

I hold a doctorate in health policy planning and administration from Brandeis University. During my tenure at the Heller School,

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I was a HCFA research fellow, working on issues of cost-related reimbursement to nursing homes and the social HMO.

In 1984, I was recruited by a $300 million company which owned, leased, or managed 290 facilities, with 31,000 beds in 12 States. In this position, I was privy to and attended many executive and strategic planning meetings.

Let me tell you first hand that decisions in the corporate area are made in the interests of making money. Quality of care issues primarily tend to surface only when forced by public exposure or by a State withholding financial payments.

The nursing home company I worked for is part of a major service corporation owning several business units: Vending and dining; textiles; magazines and books; transportation; airline services; and health care.

In 1983, the health care business segment was responsible for 12 percent of all corporate revenues and 24 percent of operating income. It was, in sum, the second leading profit center for the entire corporation.

This corporation started the nursing home company 12 years ago because it reached, and until this past year exceeded, certain financial earning thresholds. In 1984 and 1985, the corporation found a minimum earnings before interest and taxes of 10 to 14 percent and a minimum return on net assets of 24 percent to be satisfactory for the nursing home business.

In my opinion, one factor contributing to the problem of providing quality care in today's nursing homes is the percentage of profit necessary to satisfy proprietary providers.

For example, the company charter of this organization reads as follows: "To be acknowledged as a leading service management company, providing high quality, cost-effective health care while exceeding corporate objectives."

These corporate objectives are essentially the earnings figures I previously mentioned. The company's home health care unit, for example, has been curtailed because it failed to attain the financial return desired. The need for home health care services and the benefits they provide to people were not considered when this decision was made.

Other areas affected by these corporate objectives included salaries, training, staffing ratios, and facility reinvestment.

The company richly rewards its management while paying frontline workers, such as nurse's aides, essentially minimum wage. Wages and salaries are typically below that of competitors. Staffing rarely exceeds State requirements, and any training is targeted primarily at management levels.

In 1984, the company experienced a 29-percent turnover of nursing home administrators and a 50-percent turnover of director of nurses. Turnover information was not even attempted to be gathered below that level because of the magnitude of job replacements. For nursing home aides, company turnover has been estimated to run as high as 300 percent in major southern and western cities. This kind of turnover for people providing more than 90 percent of the direct care in nursing homes gravely affects quality of care.

Although one in-house study established that low pay, poor management depth, low employee morale, and the lack of training were

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prime causative factors of turnover, corporate management was very slow to consider upgrading these areas because of the expense involved.

As the industry as a whole, this company, unfortunately, is pushing to increase its census of private pay patients and decrease the number of Medicaid patients in order to maintain and increase their profits. What they found, however, is that their homes require major capital reinvestment just to remain Medicaid-competitive, let alone to attract the private pay patients.

If State and Federal Governments continue to cut nursing home reimbursements, the cuts on the facility level will not come in profits, but in staffing, food, training and plant maintenance.

For example, many administrators in Texas were disgruntled about the lack of capital reinvestment in their facilities. Some had been promised new furniture, roofs, gutters, painting, expansion, et cetera, for over 3 years, and are still waiting for these improvements. Maintenance contracts are often one of the first facility benefits to be cancelled when financial targets are not made.

One regional manager in Texas told me that over the past 6 to 10 years, the company put nothing into the facilities and bled them for every cent they made.

In a fall 1984 president's report, it was noted that the decertifications in Texas and Oklahoma cost us $505,000 in lost revenues which would have passed to the bottom line. These decertification pressures caused us to increase staffing and other costs in the Texas centers. These deficient facilities were found to have multiple problems with turnover, both at the professional and aide levels. Consultant functions, especially in Texas, are still aimed at crisis intervention.

Several people in the company reported that the Texas nursing homes were often tipped off about in-house and State surveys, which is true. It was not unusual for facilities to hire extra personnel, bring in linen, better food, et cetera, the day of the inspection and for it to vanish as soon as the inspection was over.

One facility that has been highlighted today has been cited by the State of Texas four times in the last year and was on decertification a total of 46 days, 33 at nonpayment status, the most severe category. The major reason for the decertification was patient care.

There is no question in my mind that the company will divest or sell off this facility. In fact, corporate strategy specifically states, to, "Accelerate, divestiture of unprofitable and marginal facilities with limited marketing potential to upgrade overall image and provide funds for reinvestment and acquisitions of existing operations."

At the time I left the company, they were looking at acquiring nursing homes with a minimal private pay ratio of 40 percent, and divesting one-third or 40 of their homes in Texas for the above reasons.

In summary, the corporate strategic plans state, and I quote:

> In order to maximize revenue and earnings, strategic directions for 1986 through 1990 will continue to take advantage of positive factors in the marketplace while adjusting priorities and tactics in response to the new external forces and internal changes. During the plan period, the company will:

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Continue to service Medicaid clientele in States where reimbursement rates allow acceptable profitability:

Continue to upgrade facilities and expand marketing programs which have proven profit potential, particularly through private pay census growth; and

Develop significant new business opportunities, which will both add profitable revenues, particularly from private sources, and enhance company image by providing leadership in selected market segments.

It is clear what drives this company. While profit has been the primary objective of this national chain, industry competition and regulatory enforcement have begun to push them to improve and strengthen employee training, community involvement, alternative services, and progressive planning. It is crucial that these forces continue in order to provide better long-term health care to our Nation's elderly. DRG's, as Mr. Pepper said, are causing sicker patients to be discharged into today's nursing homes. Unless the Federal Government attacks its own policies as well as corporate policies, which foster neglect and abuse, the stories you heard today will persist and will most certainly increase.

I thank you for the opportunity to testify this morning.

Mr. PEPPER. Well, we thank you very warmly, Dr. Y, for the excellent testimony that you have given us.

I would like to ask some question, starting with you, Dr. Y.

How much pay did the people who did the principal work in the hospitals receive, in the private hospitals that you served?

Dr. Y. $3.35 an hour is——

Mr. PEPPER. How much?

Dr. Y. $3.35 an hour.

Mr. PEPPER. Minimum wage?

Dr. Y. Yes, sir.

Mr. PEPPER. Minimum wage.

Dr. Y. Yes, sir.

Mr. PEPPER. For that important work, and as Ms. X was saying, you were dealing with people, turning over people that had broken bones, you know, without knowing what you were doing, not skilled enough, and people——

Dr. Y. Yes, sir. We tried to calculate the annual salary of aides. It turned out to be anywhere from $6,000 to $10,000. The average private pay patient pays the facility $20,000 to $25,000 a year, and Medicaid and Medicare reimbursement is, of course, less than that.

But, if you take a look at the caseload, if you might call it that, of the typical aide caring for 20 patients—to be conservative—a person who is earning $6,000 to $10,000 a year, is actually controlling revenue of 20 times, either $20,000 for private patients, or $10,000 to $15,000 for Government patients, and there is quite a lot of excess money there that does not go in the aide's pocket.

Mr. PEPPER. Did you—do you have any information that would allow you to make a reasonable estimate as to the profit that these proprietors were making?

Dr. Y. Yes, sir, and I have brought that in my supporting information for your perusal.

Mr. PEPPER. You filed that with the committee?

Dr. Y. Yes, sir. Yes, sir.

Mr. PEPPER. Would you rather not state a summary of it personally?

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Dr. Y. I am not a financial expert. I quoted the percentages and I best leave it to your experts to evaluate and——

Mr. PEPPER. Would you say that it is probably in excess of 10 percent of their investment?

Dr. Y. Yes. Yes.

Mr. PEPPER. Are the executives of those institutions underpaid?

Dr. Y. No, sir. Not at all. I was not, sir.

Mr. PEPPER. Could you give us some idea about salaries in the administrative area?

Dr. Y. In the administrative area?

Mr. PEPPER. The executive area.

Dr. Y. Certainly. The vice presidents in the company, of which I was an assistant to, earned anywhere between $70,000 and $90,000 in annual salary, and were eligible for a 20–25 percent bonus.

Mr. PEPPER. What was that figure?

Dr. Y. It was $70,000 to $90,000, depending on——

Mr. PEPPER. $70,000 or $90,000?

Dr. Y. $70,000 to $90,000.

Mr. PEPPER. $70,000 to $90,000.

Dr. Y. The president of the company was well over a $125,000, perhaps at a $150,000, plus his particular bonus. I would like to state that the nursing home administrators are also eligible for bonuses, and in some of the supporting information that I have brought, you will see how that is calculated. You will see that 75 percent of their bonus is based on financial incentives.

I think that will be helpful in terms of determining to what drives the regional managers who are over the individual nursing home administrators. They each have about 10 homes to supervise. They get a cut of that bonus. Then, it goes up to the executive suite, where those people and even outside the nursing home company, the head corporation in Philadelphia, those fellows get their share of the pie, too.

Mr. PEPPER. Dr. Y, did you have very much experience with inspectors, either from the Federal or State Governments?

Dr. Y. Because I was in the corporate executive suite, I myself did not have any day-to-day contact in the nursing homes, although I did frequent them as often as I could, and I have an 85-year-old grandmother in the Midwest in a nursing home.

I am well aware from my training and from word of mouth and from talking with the nurse consultants and the director of quality assurance about the inspections.

Mr. PEPPER. Were they frequent?

Dr. Y. The in-house quality assurance was done, I believe, it is four times a year. Some of those were announced, some of those were unannounced.

Unfortunately, what happened, although the company pioneered the concept of quality assurance, it soon became a moot issue. I was told by the director that the president of the company threw those reports in his wastebasket and did not care to look at them and at the graphs——

Mr. PEPPER. Threw out the reports of the inspectors?

Dr. Y. Of the in-house inspections. This company had its own in-house inspection team. Now, the State inspections, no one in the

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corporate executive suite ever looked at those, sir, until it involved litigation.

Mr. PEPPER. Did it seem to make any impact upon the institutions when these inspections occurred? State or Federal Government?

Dr. Y. I would hate to think what would be without those inspections. I am a big believer in positive incentives, in carrots as well as sticks, and I think there definitely has to be enforcement. Unfortunately, States like Texas do not enforce the way the law was intended.

Mr. PEPPER. Well, I guess there will first have to be criteria.

Dr. Y. Yes, sir.

Mr. PEPPER. Standards laid down.

Dr. Y. And, those that can continue to be refined. I personally would like to see a focus on patient outcomes, not process. Quality of life versus quality of care. Someone had mentioned earlier about having—I think it was you yourself, sir, about having elders go in and do some inspections. I think that is a wonderful idea.

Mr. PEPPER. Ms. X, what have you to say in that same area? Did you stand around in fright in expectation of these inspectors from the Federal and State Government coming around and doing a thorough job of putting you all on your uppers?

Ms. X. I never saw an inspection, sir. I worked there only 3 months. I do not know how frequently it was inspected, and the possibility exists that it might have occurred during another shift. I worked the 3 to 11 shift, but I never saw one.

Mr. PEPPER. Did you notice any—ever hear any statements from the management that they lived in deadly fear that the inspectors would be around and that they would be very exacting in their examination?

Ms. X. I did not, simply because the nursing home where I was employed was on the surface clean, it smelled good. In general, it was small enough, there were approximately 120 patients there, that it did not encounter some of the mass-produced image some of the larger homes, I understand, do.

But, you know, an inspector walks in and takes a tour, you know, someone else mentioned that it is the externals they see. In all counts there, they were doing fine. They did not hear you say sit, stay to patients. If it were there, I am not sure they would have seen it.

Mr. PEPPER. What was the pay to the institution while you were there? How much did it cost for a patient to be in there?

Ms. X. I do not know the cost of their care.

Mr. PEPPER. Did you say some $20,000–$25,000 in your——

Dr. Y. As an annual industry collection, the best statistics that I have, are for a private pay patient, someone who pays out of pocket without any insurance or Medicaid or Medicare involvement.

Mr. PEPPER. Do you know, Ms. Seidler, how much the patients pay or was paid for the patients where you are?

Ms. SEIDLER. Well, I do not know exactly how much Medicaid pays, but I do know that in my specific facility, in the health related, the private pay patients pay $2,400 a month, in skilled nursing, $3,900 a month. But, it is not the same amount in every home in the New York area. Each home has their own amounts of money

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that they charge, and I think this is—mine is about one of the highest.

Mr. PEPPER. Well, you see, this presents a very serious matter to Congress. Many thousands of dollars a month are being paid for every patient. Medicaid is carrying most of the load, Medicare a little, and we are struggling with deficits and budgets and all that. And yet, that looks like a lot of money. More money than most individuals can afford or their families, and now we go $10,000, $15,000, $20,000 per patient. And then from the evidence that we get, the patients are not very well treated, and this poses a very serious question to Members of Congress, trying to provide programs that give protection to these people.

Ms. Seidler, did you see or hear about many inspections?

Ms. SEIDLER. Oh, yes. Oh, the place is made very clean. There is no doubt about it, and everybody is on his toes, and everybody on the staff is just a little fidgety. There is no doubt about that.

However, in the past 2 years, in New York State, the surveyors have been coming to many of the residents and talking to them privately, which is something that we have been advocating for quite some time. However, the difficulty there is that the people that are interviewed are usually recommended either by administration or by the resident counsel, and we are trying now that they should be picked at random along with those that were chosen by the administration, and it is private and confidential, and that we are trying very hard in New York State to try to see——

Mr. PEPPER. So far as you observed, did the inspectors look into the qualifications of the personnel who were responsible for the care of these patients?

Ms. SEIDLER. Not really. They do not go deep enough.

Mr. PEPPER. I can well understand how the cleanliness might be observable and they would be solicitious about that.

Ms. SEIDLER. That is right.

Mr. PEPPER. But, as Ms. X has pointed out, she went to work there, I think you said, at 17, did you not, as a young——

Ms. X. There were aides there that age. I was 21.

Mr. PEPPER. Twenty-one years of age, and the—you did not have any training or competence at all for the work you were called upon to do.

Ms. X. No.

Mr. PEPPER. And, no inspector ever called you and interrogated you about your skills?

Ms. X. No.

Mr. PEPPER. Ms. Oakar?

Ms. OAKAR. Thank you, Mr. Chairman.

This has been a very interesting panel.

Ms. Tulloch, have you ever had any personal examples of abuse while in your nursing home?

Ms. TULLOCH. Very subtle.

Ms. OAKAR. Subtle examples; psychological and that sort of thing, which is a real form of abuse? You do not talk about it very often?

Ms. TULLOCH. You cannot prove it. It was a form of abuse.

Ms. OAKAR. How about you, Ms. Seidler?

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Ms. SEIDLER. Exactly the same thing. I have never—I really cannot say that there has ever been any abuse, either physically or may I say mentally. However, I have seen subtle.

Ms. OAKAR. Give me an example of subtle abuse.

Ms. SEIDLER. For instance, a bit of coldness when you ask for something, the answer is yes, sometimes the yes is really—really goes through and sometimes the yes means nothing. It is just a word, and a feeling that they are trying to shun me. They try to keep away from me for fear of what I might say or what I might do.

Ms. OAKAR. Especially in your advocacy role, it is probably even worse, isn't it?

Ms. SEIDLER. Definitely.

Ms. OAKAR. Incidentally, who told you that your father died of gangrene? Was it the doctor or did one of the aides tell you that this man had that terrible problem?

Mr. VALLEY. No. The medical report.

Ms. OAKAR. The medical report. No doctor ever told you?

Mr. VALLEY. No doctor. We never saw a doctor. Nobody from the nursing home, none of the aides. They never told us that.

Ms. OAKAR. You had to read the report, otherwise——

Mr. VALLEY. Had to read the report after he died. They sent a medical report.

Ms. OAKAR. Our last two witnesses touched on another subject that is near and dear to my heart, and that is paying people for the value of what they do, which is this national controversy. You would think we were trying to set up a nuclear warfare plan. But, the fact of it is that if you do not pay people fairly, you are not going to risk the morale on the caliber of worker pride that you need.

You both testified, and the committee report says that the person who spends the most time delivering services of this kind are nurses' aides who make the minimum wage. Am I right about that?

And, Dr. Y, you said that the middle management people were the only ones that got any kind of training, right?

Dr. Y. There was training on the books, and I was not out of the human resources department, so I did not see exactly how they did their training. But, I—the courses that I saw offered were for administrators, for people of my level—the regional managers—and above to fine-tune their skills.

The training done for aides was never done at the corporate office; people were not brought in for training. Quite frankly, probably because of the problems in shift changes and the lower staffing.

Ms. OAKAR. I heard you talk a lot about profits. We know this is the American way. Whatever you do, you try to make a living at it, so nothing is wrong with that. We do not want nursing homes to go bankrupt, but, it seems as if the discussion here is that the bottom line is always the dollar.

What percentage of the discussions that your corporate leaders had involved the quality of care for the people?

Dr. Y. Less than 2 percent.

Ms. OAKAR. Less than 2 percent.

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Dr. Y. That would be generous, quite frankly, that would be generous. The——

Ms. OAKAR. Mr. Sisisky, there are marvelous nursing homes and we ought not to indict all of them, but the fact of it is, this is a not a bad way to make a living.

Dr. Y. No.

Ms. OAKAR. If you are so inclined.

Let me ask you, Aide X, you are now attempting to go into religious work, apostolic work, which we all think you are going to do fabulously.

Ms. X. Tell my professor whose class I cut this morning to be here.

Ms. OAKAR. Well, somehow, I think you should be given extra credit. But, did most of the people you came in contact with really want to live?

Ms. X. The patients?

Ms. OAKAR. Yes.

Ms. X. Boy. Yes and no, I have to say. The classic answer is it depends on the person. I can think of examples that go both ways. I would venture to say that all of them, upon entering the nursing home, want to live. Once you have been there awhile, the tendancy—one of two things happen; either you get very, very sick because you have been admitted for terminal illness, and I mean I saw people that prayed to die every night, and I was going yeah, do it.

Ms. OAKAR. Because they could not cope with the living of——

Ms. X. Because they were in such pain, but the more tragic were the people who had given up. They did not need to give up because, except for the fact that they were in a wheelchair or except for the fact that they had something that prevented them from living alone, they were in no way mentally impaired or socially impaired or emotionally impaired, and they had every reason to have good years left.

Ms. OAKAR. Well, I am told Ms. Tulloch is the author of a book and certainly gave a brilliant statement and has a tremendous command of our language.

You know, we are going to hear, Mr. Chairman, from a very fine person from my district in Cleveland, OH. He is an ombudsman. Mr. Hornbostel and others have done fabulous work there.

But, I am reminded of a tour of nursing homes that I made in my own district. One of the patients said:

> You know, I came here to live, not to die or to be demeaned. This is supposed to be my home, and I am treated as if I am, you know, sort of on my way out and should not live a life of dignity.

I guess that is what it is all about, is it not? Did you want to comment?

Ms. SEIDLER. I have spoken to a number of people and particularly the past 8 or 9 months, I have heard more comments of people saying that they pray every night that they do not have to get up the next morning because of the conditions and also a great deal of depression. People say I do not want to be bothered, I am so depressed, leave me alone, and another thing, as far as training is concerned, New York State, our coalition, and the national coali-

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tion have been trying to pass a law that every home must have a certain number of hours of training, both on the job and otherwise. We tried to pass it last year because it was cost-containing. They did not do it. However, we are going to fight for it again this coming year.

Ms. OAKAR. You see, this is the problem. It is that you have an unskilled individual making the bare minimum, which most people could not live on, doing something very valuable, being in charge, essentially, of all these patients. A number of things have to be corrected.

First of all, you have to pay people fairly in order to attract qualified people to those kinds of professions. Second, you have to teach them the skills to deal with the situations which arise. We ought to be doing more. It sounds as if, in your case, if some support services were available, you might not even need to be in a nursing home technically, which would be a lot cheaper and more advantageous because you could have remained in your own home.

Ms. X. May I add one thing? I would like to clarify, too, just in case we are giving the wrong impression.

You know, people who go into work in nursing homes do not go in, in order to beat up old people, you know. That is not the reason they get their jobs there.

That, really, much of the subtle abuse and some of the, I imagine, physical abuse and so on is the result of ignorance from two things; first of all, the fact that there is no training in many—I am sure there are some homes that do train, but my—the place I worked cannot be the only place that does not train aides.

So, there is no real physical training going on, and the second reason is because of the low salary. It attracts people with a very low educational level, and because of that limited education, limited exposure of interaction with people, there is a decreased awareness of things that are basic in terms of dealing with respect with older people in a nursing home.

Ms. OAKAR. Let me just say that I do not condone anybody abusing anyone, irrespective of what that person is paid. I think that that is evil and wrong.

But, I will bet a lot of these people, given training, could be of great assistance, and have the compassion and interest in doing a good job.

Ms. X. They want to.

Ms. OAKAR. But, a lot of times, you know, your morale and productivity is governed by how you are treated. It seems as if we have a couple levels of abuse that have been brought out, and Mr. Chairman, I want to commend you and the witnesses and staff for this excellent hearing. I look forward to reading the rest of the testimony which will be a part of our permanent record that illustrates the extent of this national problem.

Thank you for your leadership, Mr. Chairman.

Mr. PEPPER. Thank you.

Ms. SEIDLER. May I say something else, please?

Mr. SISISKY. Thank you, Mr. Chairman.

Dr. Y, you talked about the 10-percent return. Does the State of Texas regulate the return in order to make Medicaid payments?

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Dr. Y. Not to my knowledge, sir. That return comes straight out of the corporate services office in Philadelphia. Major company that owns the nursing home company. That is dictated top down out of the——

Mr. SISISKY. Maybe you misunderstood me. The State of Texas, in order to make the Medicaid reimbursements along with the national money that goes in, whether it is 57 percent or whatever it is, you can only make so much profit in a nursing home—am I correct in that? There is not an outlandish return there.

The profit is controlled through the Medicaid reimbursement, am I correct in that?

Dr. Y. Texas has a very low reimbursement rate and probably that is inherent in the rate. That is why so many other games are played, to make profit, and why so many providers want to get out of Texas because of the low rate.

Mr. SISISKY. It is also inherent in the amount of money they pay their employees because of the reimbursement, cuts, Mr. Chairman, and Medicaid, that all plays a part——

Dr. Y. Yes.

Mr. SISISKY [continuing.] In that, and I think it should be clear that you also, in answer to a question of my colleague, said that the quality of care issue only came up in 2 percent of your discussions.

You were in the financial end of the company?

Dr. Y. I was technically in the——

Mr. SISISKY. But you were in the financial end of the business?

Dr. Y. Yes.

Mr. SISISKY. That is really not a fair assessment. I would like for the record to show that.

Well, I mean, you did not cover the total—but I just wanted that to be clear Mr. Valley, you gave a very moving testimony, and I am almost reluctant to ask this question.

Mr. VALLEY. Do not hesitate.

Mr. SISISKY. But, I have to ask this question.

Mr. VALLEY. Do not hesitate.

Mr. SISISKY. You are fairly educated. You spoke beautifully. You said you watched your father for 38 days. Did you report it to the VA or to anybody or to get a physician in there? It begs me to ask that question.

Mr. VALLEY. I will answer like this. I may have over-spoken when I said I literally watched him for 38 days. My statement should read as such: I visited dad every day for 38 days.

Now, from day 1 and the few days after that, his condition was not nearly as bad toward the end. Now, when his condition got worse, certainly we complained. We complained to the VA. We went so far as to have some representatives from the State board of health and the VA. They came out to this particular nursing home. My mother and I, we met them there, and that visit was a direct result of our complaints.

Now, we complained initially to the nursing home, but we did not get any answers there. So, we went higher up.

Mr. SISISKY. Excuse me. Your father was still alive when the VA came there?

Mr. VALLEY. Certainly. Yes.

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Mr. SISISKY. They did not remove him from the premises?

Mr. VALLEY. The day that they came to see him, this one particular day, his condition was not as bad. This was toward the middle of dad's stay. Now, his condition got progressively worse toward the last few days. I think the visit may have been maybe around the second week that dad was there, and they made some amendments. I do not know exactly what, but I think they were reprimanded pretty strongly, but——

Mr. SISISKY. That does not do any good.

Mr. VALLEY. Right.

Mr. SISISKY. Ms. Seidler, I think I know the answer to the question, but I have got to ask this question also.

If people are unhappy in a nursing home, is it because of the lack of competition in trying to get another facility to go to? Is it because of the friends that you have made there and the reluctance of people to go—and the reason I ask the question, I was a great proponent of the certificate of need in the Virginia General Assembly because I did not want the overbuilding of nursing home facilities because, obviously, you have too many spaces, the cost will go up. If you only have 60 percent occupancy versus 90 or a 100 percent.

But, I guess the strain through all of this testimony from these people that the lack of competition in this business, the inability to go somewhere else for better service, you are paying for the service, whether you are paying directly or the Government, that is your perogative, but the service is being paid for, and why is it that more people do not move on to where they can get better care?

Ms. SEIDLER. Well, you must remember when you enter a nursing home that you think it might be better. You might think it is, but when you get there, you find that it is worse.

I know we have had two or three people who came to us from a home that was considered a good home and they came because they thought ours was better, and they were disappointed.

They said they had many things in the other home that they wished they were back.

Mr. SISISKY. I can appreciate what you are saying. I wonder, what percentage of your friends in the home do have children?

Ms. SEIDLER. A large number have, but you must remember in our modern society——

Mr. SISISKY. That is what I wanted——

Ms. SEIDLER [continuing.] Children are all busy, they have their own lives, many of them are working, both the men and the women are working They have a lot of expenses. They cannot come to visit their parents as frequently as they would like. Perhaps they would not have put them in the home in the first place if they could.

In our ancient cultures, they took—you not only took care of the older people, but the older people were the dominant people in the homes. But not today. It cannot be. They cannot take care of them.

I know my daughter offered—she said she could not take my husband, it is true, but perhaps I could come. Now, what would I do in her home. She was gone all day. Her husband was gone all day. The children were gone all day. There I would be, just one person in a home doing what or nothing. I do not care for television. My

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eyes are going bad. I cannot read all day. I would be a vegetable by today if I had gone to live with her.

Mr. SISISKY. Not necessarily because, in some communities, the adult home care and the other things, the senior centers, you know, and the ability to be able to provide transportation to go there. I am not arguing with you, but I am just saying that that is available.

Ms. SEIDLER. That is available, that is true, but I am not one to play bingo or games of that kind. Most of the senior citizen homes, that is what they have, and I would be completely disinterested. Am I right or wrong? What would I do?

Mr. SISISKY. I do not think you would be disinterested in anything. I have got the distinct impression that you are a very, very independent person.

Ms. SEIDLER. Unfortunately true. I am very independent. More so, I suppose, than I should be, and as far as home care is concerned, that is an abomination. I have spoken to 10 or 15 people who have had home care and finally landed in a home. People come, they do not take care of them. One woman told me over the telephone, her stove is filthy. They do not actually communicate with the people in the home that they are supposed to be taking care of.

They just sit there and I said: "Well, what do they do?" They play television. I know of another instance where a woman had to complain to the superintendent to have her—the superintendent's son go and clean the apartment above her because of the roaches coming down because it was not cleaned.

And, in my own instance, when I was in the hospital with my last heart attack, we had somebody come into my home. She not only took very little care of him, but she robbed me blind.

Mr. SISISKY. Well, that is a shame because in some instances, in a lot of instances, home health care is very good, but the more important thing is that, you know, this Government is faced with a real, sincere problem as long as the State governments and the deficits that we have, and what we are looking for is areas that, you know, we can provide service to people who need service and try to keep them out of the nursing home, try to keep them out of there.

Adult day care, home health care, many other avenues that we have to pursue, I believe.

So, I understand what you are saying, and you are a great advocate of anything you would do, and I appreciate your being here as well as all of them.

Thank you, Mr. Chairman.

Mr. PEPPER. You spoke of the infrequency of the visits to the people who are ill, the elderly, by their children. I have known of some instances of that, and I have said that mothers and fathers should take a lot of photographs of their children right after they are born. They should show the child in his dependence and how helpless he or she is, so later on, when the sons and the daughters get grown, get busy with their own affairs and their own families, the old mother and father can pull out those pictures and show them.

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You know, the patient might say, you do not seem to have time to help me now, but I sort of would like you to look at some of these pictures of yourself. Here you are toddling across the floor, trying to walk for the first time, and on through the years, and, you know, you were not able to help yourself very much in those days. Now, I just wonder if the remembrance of those days might perhaps remind you to do a little bit better to help me now that I need your help.

My sister was telling me she was in a hospital, and there was a very lovely lady that was her roommate there. Now, one day, my sister was out and she came back after there had been a member of the family visit there, and the other lady was crying like her heart would break. My sister said: "What in the world is the matter?" Well, she said; "My daughter was just here and she tells me that she can no longer keep me in her home. They are going to send me to a nursing home tomorrow. And, I have been trying to get the doctor to promise me he will get me out."

There are a lot of people who are pushed into the nursing home by their children, some of whom could care for them, and as Mr. Sisisky has said, some could be taken care of by home care. We had a hearing in Miami one time where a lady was testifying, a middle-aged lady, and she said, "Next week, my mother is going into a nursing home because we own our home, but I'm a waitress by profession." She said, "I make about $5,000 or $6,000 a year as a waitress."

She said: "I'm the only breadwinner for my mother and me. So, I have to keep working, but if I could get $250 a month, which is $3,000 a year, my mother could stay at home and I could get stay at home with her and we could both live on that $250 a month new revenue and the Government would save what would be going to the nursing home."

Now, that seems to me such an obvious economy that you wonder why Congress has not picked it up a long time ago, but we are so sensitive about being afraid that somebody will say we are paying family members to look after their own family members, that we are hesitant about doing something like that. But, if we limit it only to those who are working and who would have to have compensation to stay at home and attend an elderly parent or member of the family, why, it would seem to me—I think they do that in England, under their program. They will pay a member of the family a certain amount for taking care of an elderly patient at home, if it is proper to do so.

So, we are going to have some more wonderful witnesses. Well, Ms. Tulloch and Ms. Seidler, Mr. Valley, and Ms. X, and Dr. Y, we are deeply grateful to all of you and appreciate your being here with us today.

Thank you very much.

Ms. OAKAR. Mr. Chairman.

Mr. PEPPER. Now, we will have a——

Ms. OAKAR. Mr. Chairman.

Mr. PEPPER. Oh, I am sorry.

Ms. OAKAR. It just occurred to me that one of the things that I think you should do, and I will go with you, and I am sure our friend here, Mr. Sisiskey will join us, is go around unannounced to

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some of these nursing homes, and commend the people who are doing a good job. We ought to take a look at those who are not doing a good job, and I think we ought to try to do that as part of committee outreach.

I know you have done it in the past, but I think we ought to put some on notice that we are going to do those things.

Mr. PEPPER. We might do that, and we might allow some of our staff to do the same thing.

Thank you all very much.

Now, then, the next panel is another outstanding group of people upon whom we are relying very much for various outstanding information.

Will you please sit at the name cards at the table? The following witnesses will now please come to the table, the Honorable Neil Hartigan, the Honorable Val Halamandaris, Mr. Richard Mahan, Mr. Roland Hornbostel, Ms. Margaret Jacks, Patricia Nemore, Nemore, and Ms. Elma Holder.

Will you come to the table, please?

[Pause.]

Mr. PEPPER. Our first witness on this panel is a longtime friend of mine. He is one of the outstanding public servants of this country.

The elderly have no better friend, and I know that he has made his office of attorney general the elderly advocate of his great State of Illinois.

I have been in his office many times. I have seen the quality and the dedication of his work, the innovations that he has brought about in the protection of the rights of the elderly, and I say again, we are exceptionally proud today and fortunate to have with us the Honorable Neil Hartigan, attorney general of the State of Illinois. I have considered him for many years one of the really bright figures in American public life, and a life has a way of going a long way, and I think he will, too.

So, I am delighted to recognize as our first witness the distinguished attorney general of the State of Illinois, the Honorable Neil Hartigan.

STATEMENT OF NEIL F. HARTIGAN, ATTORNEY GENERAL, STATE OF ILLINOIS

Mr. HARTIGAN. Thank you very much, Mr. Chairman.

Congressman Sisisky and members of the panel.

About a year ago, you were kind enough, Mr. Chairman, to meet with the Attorney General of the United States, when we formed the committee on the elderly and the law. The focus of that committee was the question that is before the Congress today: rights and the problems affecting those rights of elderly confined to nursing homes in this country.

To say that it is a national disgrace is an understatement. We heard this morning some very interesting testimony. We have heard a cross section of opinion on a variety of different elements dealing with individuals in nursing homes.

I would like to focus, if I might, not on the homes that do a good job and there are homes and we salute them for them, thank good-

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ness they are in existence, but, rather, on those that beat the system.

The role of the Federal Government and the role of the State governments in many of our States has been an embarrassment to civilized human beings, and I mean that very sincerely.

The mark of civilization used to be when we stopped abandoning the elderly and the deformed and disabled, literally in the deserts. That was the Hebraic tradition. Now, we have got a new kind of society. It is a disposable society. Not just in terms of pop bottles; it is disposable in terms of human beings and that is what is happening in too many of the nursing homes in this country today.

This is supposed to be a shared responsibility. In Illinois, 64 percent of the beds are bought with Government money, tax money. Federal tax money and State tax money. Frankly, there is way too much political influence. We ought to get politics out of the nursing home industry in this country.

Now, one of the ways to do that, by the way, would be to indicate that they could not make political contributions to anyone, to anyone. This kind of a regulated industry, as much as I am for the free enterprise system, should not have the degree of influence that it has over Government policymaking.

I have heard a variety of different elements discussed here today. Legislation is one piece of it, but when you go from legislation, then you go to regulation, you go to inspection, you go to enforcement, and you go to prosecution, and it is that chain of events where the system breaks down.

Someone responded to you, I think, Congressman, earlier today, when you asked the question, I believe, what was the underlying—what was the one word that was underlined, and I think Mr. Douglas said greed. He is right.

The people that the legislation should be focused on are not the ones that are doing the job. I heard it explained one time, Mr. Chairman, the guy said, well, if the cost of a spoonful of beans is a penny, and there are three meals a day, that is 3 cents. If there are 200 patients in the nursing home, if that is the census, that is $6 a day times 7 days a week is $42, 4 weeks in the month, $168, times 12 months in the year, comes out to roughly $1,400.

That is by accepting one spoonful of beans in the diet. What we are hearing about is the other elements, whether, in fact, the wages paid to the aide are adequate or not.

Is there one or two less nurses on the night shift than there should be. Is the maintenance performed or is it not? Are the funds that are supposed to be available to the individuals of $25 a month, for instance, for personal needs, are they converted to use of the people in the homes.

You know, I have been in Government a long time. I have had the responsibility, by the way, when we were talking about licensing earlier, I used to have the responsibility for licensing in the city of Chicago. We initiated an attempt to drive the syndicate out of the liquor licenses. There, there were all sorts of pressure that we were able to bring to bear, and that was one to one crime, you know. Prostitution, narcotics, whatever it might be. One to one violations.

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But that does not exist in this area. It might be 100 to 200 or whatever the census might be in the nursing home. So, I think the focus question is an important one.

Certainly, we want to protect the rights of the people in the industry on a legitimate basis. We want to encourage them, but we better change Government policy, Mr. Chairman, and nobody has tried harder than you have, and we better change it quickly because our public policy is not to encourage, as Congressman Sisisky was asking about earlier, homemaker and home health care. That is not where the buck is. The buck is by forcing well people in to homes and then providing substandard care in those homes.

Today, I would like to focus on a number of things, some practical examples, I think, of what might be of some help. In all the time I have been in Government, this hearing, I think, is perhaps the most important one I have ever had the privilege of attending because we are not talking about statistics here; we are obviously talking about human beings and the ones who are least able to protect themselves in the society.

With respect to the question of abuse and neglect of nursing home patients, in Illinois, the lack of basic enforcement of human rights and the lack of prosecution of nursing homeowners for abuse and neglect is evident in the basic State's statistics in this area. The Federal Government has allocated massive financial resources to detect abuse and, in fact, nothing happens. For the first 5 years of the act, there was not one successful license revocation hearing in the State of Illinois. We could revoke 200 liquor licenses, but not one nursing home license was revoked.

I brought with me today some pictures of a public aid patient who died of gross dequibitous bedsores in 1983. Only after the threat of a lawsuit by the Attorney General's office did the State public health agency rescind its order to settle the case. They were going to settle this case for $1000. After a hearing prosecuted by our attorneys, the first license revocation of a nursing home in Illinois was accomplished.

This is not sensationalism. This is basically what we are talking about, and what Mr. Douglas was talking about that he found.

That is Margaret Ashcraft, used to be Margaret Ashcraft. All right. I have copies of this that I would like to submit to the committee, by the way, for your records, if I might.

Mr. HARTIGAN.—Margaret Ashcraft—when Margaret Ashcraft died, when she died, that woman had 29 bedsores. This is her hip and her buttocks. If anybody has ever been involved in their own family—if anybody has ever been involved with one bedsore, just roll over once, you know what it feels like.

From here to here, the woman had 29 bedsores. You could not tell she had a hip, as those photographs point out, and we could not get a hearing, could not even get a hearing, from the Department of Public Health. That makes no sense, and it is wrong.

The Illinois Department of Public Health did not follow through on its administrative responsibilities. We have now gone to grand juries, and I think that is the answer. Criminal prosecution for patient abuse, make them felonies, and enforce them, and I would like to suggest, Mr. Chairman, that the Federal Government do just that.

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How can the Federal Government allow hundreds of millions of dollars to be misapplied in the manner that it has been in terms of the type of patient care that is involved and never, never, to the best of my knowledge, has there been a Federal prosecution of a nursing homeowner or administrator or a State official. State official who does not enforce the regulations and who fail to conduct decent inspections, enforce the people under his or her area of responsibility to do the job that they are supposed to do.

I would suggest Federal legislation is needed which would penalize State enforcement agencies which refuse to protect the rights of the institutionalized elderly.

Second, consumers and taxpayers should be aware of where the State stands, vis-a-vis other States, in regard to enforcement of nursing home statutes. A national rating guide would be an appropriate vehicle to identify which officials are taking a back seat on this issue.

Examples of information to be included in the national rating guide could be the number of licenses revocations in each State, number of criminal prosecutions for abuse and neglect, the number of nursing homes fined for fraud and abuse of Government funds, the number of Medicaid fraud unit prosecutions for patient abuse and neglect.

Third, the Federal inspector general must conduct an audit of patient trust accounts and develop appropriate guidelines for State Medicaid agencies to utilize—to be utilized in the detection of fraud.

Federal matching funds—Medicaid—should be tied to the successful implementation by the States of these guidelines.

I suggested, when I became attorney general, that the Federal Government take its computer and the State government take its computer and that we cross-reference the complaints and the record as far as the adjudication, if you will, of those complaints or prosecution of those complaints. We should compare this process to revocation of liquor licenses. We have more liquor licenses in the city of Chicago than there were nursing homes in the State of Illinois.

To do a history on them, you could tell if a place was a bust-out joint or not, by the type of allegations that were taking place and what the results were. A liquor license fee, if that person's license was revoked, Mr. Chairman, members of the committee, you could never hold another license for anything for the rest of your life. Anybody who had more than 5 percent of the corporation could not either. The premises could not be used for a year.

Well, if that is true in that one-to-one violation, then why is it not true in the nursing home area? Nobody, nobody who has their license revoked for patient abuse in a nursing home should ever hold another license in this country. They should be out of that business and, frankly, they should be criminally prosecuted as well, and so should the other people in the home.

What we have got is we have got—we do not have human beings in terms of these human sleazes that are engaged in this aspect of the business, and I draw, Mr. Chairman, Congressmen, the distinction very carefully. We have wonderful people that own and manage some of these homes.

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I am not talking about them. I am talking about the hustlers that know how to beat the system, that see wave after wave every 2 or 3 years of another nursing home scandal in our State or in other States. All they do is they go low until the heat blows over and then they come back in and go right back into business again, you know, as outrageously as they were before. That is what has to end, and Federal prosecution, Federal laws, criminal laws across this country on a uniform basis is the place to start with it.

The U.S. attorney, the FBI, when you have got hundreds of millions, in fact, billions of dollars involved in health care, I have never seen them used, and, I think, we could get everybody's attention much more quickly. Take the computers, cross-reference the complaints, it would give us a profile very quickly of what are the 50 or the 100 places that are the worst violators of patient abuse in our State or in other States, and on a joint Federal/State basis, crack down on them. In a year, you could eliminate a massive amount of, percentage wise, patient abuse that is going on.

It is just common sense, but there is no followthrough on it at the Federal levels. So, I would suggest that the effort that you have undertaken again and the leadership that, thank goodness, you are providing, that that area of criminal violations, Federal criminal violations and the use of Federal enforcement against both the people in the homes—I am sorry. The people owning those homes and the State administrators would be a very good idea.

Mr. PEPPER. Excuse me. Mr. Hartigan, as a lawyer, you can answer this. Would we have to enact Federal legislation prescribing the duties of these proprietors so that if they violated that duty, it would be a criminal act, and then the Government could prosecute? Or do you think legislation exists now that would permit that?

Mr. HARTIGAN. I think there is enough already on the books in terms of the responsibility that they have.

I think it is enforcement much more so, sir, than the law itself. I mean, there are some real hustles going on in this area, and the best investigators, the best enforcement is at the Federal level, and we need that kind of help. You know, this is a society where we can have—we rate restaurants, we rate hotels, we have got five-star guides, try and find out before you put your parents in a nursing home or before a person puts themself in a nursing home what kind of home it is.

Why is there not that kind of rating publicly available? I suggest then that there be joint license revocations and that no money, especially no Federal money, be allowed to go into those homes that violate the basic rights, that the licensee be ineligible of ever holding a license for that premise—I'm sorry—for that purpose for the rest of their life.

Receivorships—one of the differences between the tavern that I mentioned and the nursing home is that one of the ways that the hustlers beat it is that they say well, you know, what are we going to do with the people, what are we going to do with them. Well, the answer is in terms of removal of them, which does cause some medical problems, bring receivors in, qualified receivors could take over the administration of that particular home.

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These are Government funds in many respects that are involved here, and those statutes are not enforced in many States, they are not on the books. It should again be a Federal activity.

We have got hospitals, hospitals that have all sorts of beds now available to them because of the difference in terms of long-term care activity, where, in fact, high quality care could be provided. So, I think it goes back, Mr. Chairman, to the initial Federal policy and State policy in terms of homemaker and home health care, encouraging that kind of activity, be very supportive of the good homes, and crack down on the criminal basis with the homes where there is the patient abuse that is involved.

In terms of Medicaid decertification, those areas I have covered in the testimony that I presented to you.

Mr. PEPPER. Mr. Hartigan, you will have to excuse me. There is a vote on, and I will have to run over and vote, but I will be right back. I am sorry.

[Pause.]

Mr. PEPPER. The committee will come to order, please.

I am sorry that I had to absent myself, but we were voting on the continuing resolution on the floor of the House, involving a good many billions of dollars. Mr. Hartigan will remember that his State's former U.S. Senator, Senator Edward Dirksen, was reputed to have said on one occasion that "You take $1 billion here, $1 billion there, $1 billion over there, first thing you know, you are talking about real money." And now, you can go ahead, Mr. Hartigan.

Mr. HARTIGAN. Mr. Chairman, the two other things that I might move through somewhat quickly is with respect to the Medicaid certification, requiring contributions from families of Medicaid patients as a condition of the patient's admittance or continued residence in a nursing home is one of the abuses that we found.

Second, discharging former private pay-residences, once they become Medicaid eligible, because they have exhausted their resources is another problem.

Third, requiring Medicaid eligible applicants for nursing home care to pay private pay rates for specified periods before converting to medical assistance.

And, fourth, discharging Medicaid patients from a facility to a hospital in order to make room for private paying residents.

I asked our senior citizen advocacy division, which is chaired by Eugenia Chapman, who is over to my left and who you met on previous occasions, to draft legislation aimed specifically at prohibiting Medicaid discrimination in Illinois.

The bill is now awaiting Governor Thompson's signature. The Federal Government should require similar laws in all Medicaid participating States because Medicaid is a joint Federal/State program, and the practices of Medicaid discrimination are nationwide. I would like to submit the following additional legislative proposals to you:

First, establish a mandatory minimum 10-day bed-hold law. Currently, there is no such requirement. However, several States have adopted their own bed-hold policy. A bed-hold law would prevent a nursing home from dumping a resident in a hospital and then filling the Medicaid bed with a private-pay resident.

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Second, require that if a facility requests Medicaid certification, the entire facility be Medicaid certified. Some nursing homes have entered into a limited bed provider agreement with their State Medicaid agency.

By entering into an agreement of this nature, Federal and State Governments are sanctioning limited access to Medicaid residents.

Third, prohibit distinct part certification. Distinct part certification occurs when a nursing home certifies only a floor or a wing of a nursing home. Distinct part certification requires all Medicaid recipients to live in that certificated portion of a facility.

Intrafacility transfers made necessary by distinct part certification can discriminate against the individual who has been so transferred.

The last thing I would like to comment on is a new phenomenon, Mr. Chairman. You have come across it before. Unlicensed nursing homes—it is a dumping group.

Aside from the problems suffered by the elderly in licensed facilities, there also exists an even greater threat in the form of the so-called unlicensed homes.

In essence, these facilities consist of nothing more than dilapidated, filthy, roach-infested buildings used to house elderly, disabled, and mentally handicapped citizens. Many of these individuals require the type of care which would mandate the owner to obtain a license to operate, but they do not get it.

In March 1984, investigators from our office, armed with a search warrant raided a building on the south side of Chicago. They had to use boltcutters and crowbars to gain entry because both the front and the rear doors had been secured with iron bars.

Once inside, they observed nothing short of a nightmare.

This home consisted of three floors; each housing elderly and disabled individuals. Toilets were filthy and malfunctioning, resulting in residents using coffee cans for urinals. Many residents slept on bare mattresses covered with roaches.

One resident told investigators that they had been kept prisoner by the operator. Others described their life as like living in a prison. Many required nursing supervision as well as medications. These 14 residents were transferred to a licensed facility.

Further investigation revealed that many of these residents were receiving Federal assistance through Social Security benefits as well as State public aid. We also discovered that many residents never saw their checks because they had been intercepted by the woman who owned and operated these facilities.

This scheme, according to our prosecutors, resulted in an illegal cashflow between $30,000 and $40,000 a year channeled to the owner. Just transferring over those checks; 1 week after the residents were removed, fire destroyed the building and killed the owner. Had we not acted, 14 innocent senior citizens would have perished as well, trapped inside a locked building. Numerous other cases have been discovered by our office.

This hidden industry, which feeds on the helpless, is a target of both civil and criminal actions in our office at the present time. We have filed numerous actions to close unlicensed homes, which engage in neglect, abuse, and defraud the elderly. The most difficult part of this task has been locating those homes.

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One method to accomplish this task would be for Federal and State authorities to utilize their computer system to cross-check the number of checks going to a particular address. This, in turn, should provide a tool for guiding agencies to suspected unlicensed homes. Once these addresses are identified, there should be no excuse why health agencies cannot systematically check each address to ensure there is no violation of the law. If a violation is discovered, then the case could be immediately forwarded to the proper Federal or State agency.

I urge the subcommittee to take this action to expose in the light of public scrutiny the underground network of unlicensed homes which profit from the suffering of our Nation's elderly. Only with your help can we begin to correct what I believe to be a national disgrace. To do less is to condemn hundreds, in fact thousands, of helpless citizens to a life of secret neglect and death in this.

[The prepared statement of Mr. Hartigan follows:]

PREPARED STATEMENT OF NEIL F. HARTIGAN, ILLINOIS ATTORNEY GENERAL

I am grateful to have this opportunity to present testimony before the House Select Committee on Aging's Subcommittee on Health and Long Term Care. The issues before this body today are of the utmost importance to the institutionalized elderly of America.

As the Chief Legal Officer of the State of Illinois, I am committed to improving conditions of the institutionalized elderly. I have allocated the resources of my office to organize a Nursing Home Strike Force whose primary purpose is to address the abuse and neglect of nursing home residents, detect and investigate cases of nursing home fraud and seek to impose through the criminal justice system, stiff fines and penalties for all of these crimes against the elderly.

Attacking unscrupulous nursing home owners is a herculean task, at best. In 1979, the State of Illinois passed legislation which was among the most extensive reform in the nation in the area of safeguarding the rights and care rendered to the nursing home patient. Illinois' experience in enforcing this landmark legislation since 1979 has been abysmal. Our state has the ability to utilize the mechanism of receivership in license revocation situations. Illinois state officials charged with the responsibility to utilize this mechanism chose to ignore it for the first four years of the Act. No licenses have been revoked during the first four years of the legislation and, no Medicaid decertifications have occurred although the state has lost millions of dollars for nursing homes which failed to meet minimum standards for participation in either the Medicare or Medicaid government programs. This track record is appalling. Due to the intervention of my office in 1984, the state finally conducted an administrative hearing into the negligent death of a nursing home resident, Margaret Ashcraft.

MEDICAID DISCRIMINATION

The prevailing system of discrimination that I am speaking of here today is unique and insidious in that it is not aimed at any particular minority, religion, or ethnic-group. It is a type that discriminates against the very old, the very sick, the very poor, and in short the most vulnerable segment of our population. It is the kind of evil that a number of states such as Illinois, Florida, California, and Ohio have addressed by enacting innovative legislation.

Nursing Homes often practice the following types of Medicaid discrimination in order to maximize their profits:

1. Requiring contributions from the families of Medicaid patients as a condition of the patients' admittance or continued residence at the nursing home;
2. Discharging from their facilities former private-pay residents once they become Medicaid eligible because they have exhausted their resources;
3. Requiring Medicaid-eligible applicants for nursing home care to pay private-pay rates for specified periods before converting to medical assistance; and
4. Discharging Medicaid patients from the facility to a hospital, in order to make room for private-paying residents.

For example, a woman 60 years of age—I will refer to her as Mary—is a Medicaid resident in a skilled nursing home as a result of a brain injury sustained in a car

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accident. Mary is a spastic quadriplegic, unable to communicate, unable to self-feed by mouth, unable to control her bowels and unable to make coordinated movements.

On March 16, 1984, Mary was transferred to a hospital due to an illness—possible pneumonia. She recovered in four days and attempted to return to the nursing home. But the nursing home administrator told her husband that her bed had been filled with a private-paying resident.

In addition to being a hardship for Mary, this costs the taxpayer money. Mary has been a patient in a private hospital since March of 1984. The State of Illinois has paid approximately $320 each day for her care. The daily public aid reimbursement rate for nursing home care is $35. The State of Illinois has over spent approximately $150,000 because none of the Medicaid certified nursing homes in Mary's area wants her. They refused her access because the Medicaid rate is supposedly too low and Mary requires constant care which translates into low profits to the nursing home.

Let me recite to you another example of Medicaid discrimination. A woman, 70 years of age, is threatened with discharge from a nursing home because and I quote "due to the amount and size of her defecation, the main sewer has been stopped up and on 3 different occasions in the last year, emergency plumbers have been called to rotor root the main sewer." I ask you, what was the real reason for her threatened involuntary discharge? I'll tell you, it was profit motivated. The nursing home administrator told one of her relatives that "I am trying to remove all Public Aid residents from the home because private-pay residents bring in more money."

I asked my Senior Citizens Division to draft legislation aimed specifically at prohibiting Medicaid discrimination in Iilinois. The legislation, HB1410, passed the Illinois Senate and the House of Representatives in June. The bill is now awaiting the Governor's signature. The Federal Government should require similar laws in all Medicaid participating states.

Because Medicaid is a joint federal-state program and the practices of Medicaid discrimination are nation-wide; I submit the following additional legislative proposals to you:

1. Establish a mandatory minimum 10-day bed hold law. Currently, there is no such requirement; however, several states have adopted their own bed hold policy. A bed hold law would prevent a nursing home from dumping a resident in a hospital and then filing the Medicaid bed with a private-paying resident:

2. Require that, if a facility requests Medicaid certification, that the entire facility be Medicaid certified. Some nursing homes have entered into a limited bed provider agreement with their state Medicaid Agency. For example, a Medicaid Agency certifies only 10 of the nursing home's 100 beds. Access to Medicaid patients is therefore very limited. By entering into a agreement of this nature, the federal and state governments are sanctioning limited access to Medicaid residents. A nursing home certified to accept Medicaid patients should not be given the opportunity to pick and choose whom they want to take. The criteria should be: (1) is the person Medicaid eligible; (2) is there a vacant bed; and (3) does the home provide the appropriate level of care, i.e., skilled or intermediate care?

3. Prohibit distinct part certification. Distinct part certification occurs when a nursing home certifies only a floor or wing of a nursing home. Distinct part certification requires all Medicaid recipients to live in the certified portions of a facility. Intra-facility transfers made necessary by distinct part certification can result in transfer trauma. Also, moving to a new room when converting to Medicaid is stigmatizing and humiliating for many former private-pay residents. One of every three nursing home residents will eventually have to go on Medicaid.

PERSONAL NEEDS ALLOWANCE

Elderly nursing home patients receive $25.00 per month for personal needs times. This amount is to be used for basic needs which are not covered by provisions of the government financed program. It is difficult to recommend an increase in this area when it is apparent that widespread fraud is taking place in the entrustment of those funds. It is my opinion that there is a need for effective enforcement measures by government officials to ensure those funds are getting to those patients. Medicaid Fraud Control Unit in Illinois has a woeful record in preventing fraud in this area and consequently patient funds are at the mercy of unscrupulous nursing home operations.

ATTORNEY GENERAL TASK FORCE . . . IMPETUS FOR LEGISLATIVE REFORM PHYSICAL AND MENTAL ABUSE AND NEGLECT

The lack of Illinois enforcement of basic patients rights and the prosecution of nursing home owners of abuse and neglect is evident in the basic state statistics in

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this area. The Federal Government has allocated financial resources to detect abuse and neglect through Medicaid Fraud Control Units. Since their inception, the State of Illinois has investigated and prosecuted just one case of patient abuse or neglect. Due to this deplorable track record, I have taken steps within to the offices of the Illinois Attorney General to protect the rights of the institutionalized elderly.

Also, in 1984, my office convened a Nursing Home Advisory Council which is composed of professionals (medical and legal) interested in improving the conditions of nursing homes. This body recommended numerous substantive improvements to the current state system which were subsequently incorporated into Illinois Senate Bill 1935 that passed the Illinois General Assembly in July 1984 and was signed into law that year. The changes which specifically address the issues under discussion today include the following:

Abuse: The revised legislation defines abuse as intentionally or knowingly causing any physical or mental injury or committing any sexual offense. Offenders are guilty of a Class 3 felony, punishable by two to five years in the penitentiary.

Neglect: The revised legislation defines neglect as failing to provide adequate medical or personal care or maintenance resulting in physical or mental harm to the patient's condition. A person guilty of gross neglect is guilty of a Class 4 felony, which is punishable by one to three years in the penitentiary. Also, If a licensee or owner causes gross neglect through negligence in hiring, training, etc. he is guilty of a business offense carrying a fine up to $10,000.

The legislation provides a vehicle for state officials to enforce one of the most crucial areas of nursing home care. Unfortunately, absent a firm conviction on the part of government officials to enforce these provisions, the legislation merely represents a "good idea on paper". My Strike Force has encountered significant reluctance on the part of state government to aggressively investigate cases of abuse and neglect in order to obtain criminal convictions in this area. To date, my office has received only eight cases of "Type A" or the most serious type of violation from the State Department of Public Health. The new legislation became effective in January, 1985. Nine months have elapsed and not one significant case of gross neglect or abuse has been referred to this office. The Department is incapable or unwilling to conduct quality investigations in this area. The nurses are unable to conduct an investigation into severe bedsore cases. The general investigation finding in these cases of gross neglect is "inappropriate medical documentation" on the part of the nursing home.

Due to this fact, I am convening a special meeting of the Medical Subcommittee of the Nursing Home Advisory Council on October 2, 1985. The task set before this group will be to develop appropriate investigative guidelines for the review of gross neglect cases which relate to bedsores.

I have brought pictures of Public Aid patient who died of gross decubitus bedsores in 1983. Only after threat of lawsuit by the Attorney General's Office did the State Public Health Agency rescind its offer to settle the case for only a $1,000 fine. After a hearing prosecuted by my attorneys, the first license revocation of a nursing home in Illinois was accomplished.

The Illinois Department of Public Health has failed to fulfill their administrative responsibility. My office has begun to use grand juries to investigate acts of abuse and neglect. To date, we have over a dozen cases in County Grand Juries with more Grand Jury investigations anticipated.

We intend to indict and convict the individuals responsible for the abuse and neglect. We also intend to indict and convict the corporations who have been sheltered, insulated from responsibility. We intend to put those corporations who abuse and neglect the institutionally aged permanently out of business

PATIENT'S PERSONAL FUNDS ACCOUNT

The abuse of personal needs allowances of the institutionalized elderly has been widely recognized for the past ten years. Although there have been regulations for the safeguarding of these funds, little enforcement has taken place in this area. The $25.00 monthly allowance is routinely taken by some unscrupulous nursing home owners in the form of an interest free loan. Upon a government audit, the nursing home may or may not return these funds to the elderly patients. Often, the state welfare agency identifies abuses in this area but fails to take decisive action in recoupment of these funds. In Illinois, there have been several Legislative Investigating Commission reports which have outlined the extent of the problem. To date, the state welfare agency has failed to take effective action to protect the funds of the elderly.

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The Federal Government reviewed the issue of management of patient trust funds extensively in the years 1976–1980. Regulations were proposed in 1980 which would have assisted government agencies in requiring nursing homes to adequately document the handling of patient trust funds. The regulations required nursing homes to maintain their records in accordance with the American Institute of Certified Public Accountants' Generally Accepted Accounting Standards. This requirement would simplify the audit process and would alleviate the often heard excuse of nursing home owners that "it was merely a book-keeping error".

Unfortunately, the regulations were stayed in October, 1980 due to a change in Administrations. I think the results of this action are self evident. Abuses continue to occur at the expense of the patient.

RECOMMENDATIONS

1. Federal legislation is needed which would penalize state enforcement agencies which refuse to protect the rights of the institutionalized elderly.
2. Consumers and taxpayers should be aware of where their states stand vis-a-vis other states standing in regard to enforcement of nursing home statutes. A national rating guide is an appropriate vehicle to identify which officials are taking a "back seat" on this issue. Examples of information to be included in a national rating guide include: (1) number of license revocations in each state (2) number of criminal prosecutions for abuse and neglect (3) number of nursing homes fined for fraud and abuse of government funds. (4) number of Medicaid fraud unit prosecutions for patient abuse and neglect.
3. The Federal Inspector General must conduct an audit of patient trust accounts and develop appropriate guidelines for state Medicaid agencies to utilize in the detection of fraud. Federal matching funds should be tied to the successful implementation by states of these guidelines.
4. As a requirement of participation in Medicaid, all states should enact and enforce a model nursing home receivership statute.

UNLICENSED "NURSING HOMES"

Aside fom the problems suffered by the elderly in licensed facilities there also exist even a greater threat in the form of so called "unlicensed homes". In essence these facilities consist of nothing more than dilapidated, filthy, roach infested buildings used to house elderly, disabled and mentally handicapped citizens. Many of these individuals require the type of care which would mandate the owner to obtain a license to operate.

In March of 1984, investigators from my office armed with a search warrant "raided" a building on the Southside of Chicago. They had to use bolt cutters and crowbars to gain entry because both the front and rear doors had been secured with iron bars. Once inside what they observed was nothing short of a nightmare. The "home" consisted of three floors each housing elderly and disabled individuals. Toilets were filthy and malfunctioning resulting in residents using coffee cans for urinals. Many residents slept on bare mattresses covered with roaches. One resident told investigators that he had been kept "prisoner" by the operator. Others described their life as "like living in a prison". Many required nursing supervision as well as medication. These fourteen residents were transferred to a licensed facility.

Further investigation revealed that many of the residents were receiving both federal assistance through Social Security benefits as well as state public aid. We also discovered that many residents never saw their checks because they had been intercepted by the woman who owned and operated this facility. This scheme, according to my prosecutors, resulted in a illegal cash flow of between thirty and forty thousand dollars a year channeled to the owner. One week after the residents were removed fire destroyed the building and killed the owner. Had we not acted, forteen innocent individuals would have perished trapped inside a locked building.

Shortly following this incident another "home" was closed as being an unlicensed facility. Again the living conditions were declared "unfit for human habitation" by the city health department. Again the operator was found to be receiving both social security and welfare checks. One elderly resident was found malnourished and covered with bedsores. A lawsuit was filed to close this "home" as a health hazard and the owner has been charged criminally.

My office has made this "hidden industry" which feeds on the helpless, a target of both my criminal and civil divisions. To date we have filed numerous actions to close unlicensed "homes" which neglect, abuse and defraud the elderly. The most difficult part of this task has been locating these homes as a predicate to effective enforcement actions by the appropriate state and federal authorities.

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One method to accomplish this task would be for the appropriate federal and state authorities to utilize their computer systems to cross check the number of checks going to a particular address. This in turn should provide a tool for guiding agencies to suspected "unlicensed homes". Once done there should be no excuse why health agencies cannot systematically check each address to ensure they are not operating in violation of the law. If illegality is discovered then the case could be immediately forwarded to the proper federal or state agency for prosecution.

I urge this Subcommittee to address this underground network or "unlicensed homes" which feed off the suffering of our nation's elderly and disabled citizens. Once exposed to the light of public scrutiny only then can we, as fellow citizens, begin to correct what I believe to be a national disgrace. To do less is to condemn hundreds of helpless citizens to a life of secret neglect and death in an abyss of apathy.

Mr. PEPPER. Thank you very much, Mr. Hartigan.

We appreciate your testimony, and we will have some questions in a minute.

The next witness is also a longtime friend, and a very distinguished man. Former chief investigator, U.S. Senate Committee on Aging, and Director of Oversight for the Select Committee on Aging of the House of Representatives, of which I was chairman.

He is a distinguished author, coauthor of the book, "Too Old, Too Sick, Too Bad." Today, he is chairing one of the great national organizations in the field of health. He is a man who, for many years, has been the leader in the recognition of the problems of the elderly and also a leader in trying to solve them.

The Honorable Val Halamandaris.

STATEMENT OF VAL HALAMANDARIS, FORMER CHIEF INVESTIGATOR, U.S. SENATE SPECIAL COMMITTEE ON AGING, AND DIRECTOR OF OVERSIGHT, U.S. HOUSE SELECT COMMITTEE ON AGING, COAUTHOR "TOO OLD, TOO SICK, TOO BAD." WASHINGTON, DC

Mr. HALAMANDARIS. Thank you, Mr. Chairman, for proving that Thomas Wolfe was wrong. Thomas Wolfe wrote, "You can never go home again," and you have made it very, very clear that you can come home again. I am delighted to be here. You honored me years ago in letting me work with you and you honor me again today by soliciting my opinion on this important topic.

I would like to yield myself 3 minutes, if I may, Mr. Chairman, to summarize the remarks and maybe synthesize what has happened heretofore.

I have devoted, I guess, the better part of my adult life to an examination of the problems of the abuse of the elderly. Let us all admit that they are significant and they are widespread. Let us also admit that they exist not only in nursing homes, but they exist in private homes, that they are perpetrated not only by venal nursing home administrators, but perpetrated by individual family members, and let us also admit that there is going to be a significant problem of abuse in home care unless you, Mr. Chairman and the members of this committee, come in to head it off.

I think that we need to recognize responsibility, the responsibility of Government, for bringing those scandals to roost. I am predicting that unless the Congress intervenes, that 2 years from now, you are going to be having hearings about fraud and abuse in the home care field, and I worry about that greatly, and I would like to sound the alarm today.

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If we admit that there are abuses, let us also admit that we have made tremendous progress. If we admit that there are problems, let us also admit that we have made tremendous program in the last 10 years. Mr. Chairman, you introduced an amendment which made it a felony for people to charge somebody for the privilege of going into a nursing home and having Medicaid pay for it. It is on the books.

Your amendment made it a felony to accept kickbacks in the Medicaid Program, Medicare Program. That was Public Law 95-142. Years ago, we did not license nursing home administrators. Now, they are required to be licensed in every State. We have not had a nursing home fire in how long? Last one we had, you and I together inspected it, and I remember, as you do, the smell, when you go into one of those facilities, where people have died. It stays with you the rest of your life. We have not had one in 10 years.

We have made progress, Mr. Chairman. Not as much progress as we need to make.

Now, when it comes to responsibility, I would like to quote that eminent cartoon, Pogo, to you. Pogo said, "We have met the enemy and he is us and there is enough blame to go around." Some of the blame lies with nursing home administrators and owners. Indeed, they have the primary responsibility, but the responsibility also needs to be meted out to other aspects of society.

For example, we concluded years ago that there are five basic root causes of the problem you are dealing with here today.

No. 1 is the physicians avoid nursing homes and you saw that in your own chart. Physicians do not go to nursing homes. Part of the problem being that physicians do not think the kind of positive reward that comes—associated with seeing people get better or cured is not to be found in a nursing home. This is called the Marcus Welby syndrome by some people, and the fact of the matter is people in nursing homes can make dramatic improvements, sometimes all you have to do is take them off of all of the different kinds of drugs that they take.

So, physicians avoid nursing homes, and I would like to credit you, Mr. Chairman, because you have created a department of geriatrics and department of gerontology at Florida State University. Dr. Robert Butler has done the same thing. Those are the only two that I know of in the country, trying to get physicians more interested in going into nursing homes and caring for the elderly.

In the long run, that is what is going to make the major difference in the quality of care.

The second, second major root cause that we have identified again and again is the financial incentive in the Medicare and Medicaid programs are aligned in such a way to guarantee poor care. The message that nursing homeowners are receiving at the present time from Federal Government is cut costs.

The Federal Government is in league with the corporate executives that you heard about in the last panel in that only 2 percent of the time that we as Members of the Congress and as representatives of health care financing administration has spent talking about quality.

I do not know, I have not seen a statement in the Congressional Record for the last 5 years that talks about the quality of nursing

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home care. What we have been talking about more and more is the need to come to grips with the budget deficits. They are very real problems, but we lose sight of what is important, which is quality.

So, financial incentives are lined up in the wrong direction. Nursing home administrators do not have any incentive to provide high quality care. They do not get more, they get paid less if they provide good care.

The third major root cause is that the enforcement system simply does not work. I have alluded to several statutes which are on the books on the Federal statutes. The U.S. attorneys do not take the time to enforce these statutes. They believe it is penny-ante. They believe it is not significant.

They tell me that they have got senior citizens that are on one side complaining about the problem and maybe physicians on the other. Physicians are armed with the best lawyers that money can buy. Senior citizens that may or may not remember what happened to them in the context of a particular situation.

So, the U.S. attorneys find these cases are difficult to prosecute. Fraud cases are hard to make, and they also tend to view them as unimportant; I think a reflection of their view of the elderly's place in society.

The enforcement system also does not work in Medicaid. It used to work very good in Medicare before we gutted the Medicare nursing home program, and we in Congress sat back and allowed the health care financing administration, HEW, to cut back dramatically the dollars that were going in to the Medicare nursing home program.

It used to work well. It does not work well in Medicaid. Why? Because you have got a bifurcated program in which both the Federal Government and the States are responsible for enforcing the standards that exist. It is Amos and Andy playing baseball. It is, I have got it and you take it and the responsibility falls between the cracks.

Somebody, in the Federal Government, I posit to you, on the statute, has the primary responsibility for making sure that patients are protected.

Now, there is a need for more statutes. There are some clarifications. The idea that you suggested about patients' bill of rights and making them stronger and allowing some sort of private right of action by attorneys is significant. You should go with that, I believe.

Two other points, if I may, which is we mentioned again and again the primary root cause of the problem is the reliance on untrained personnel, and, again, we have got to look at Government here for some of the responsibility because it is Medicare and Medicaid that is telling the nursing home administrator that the one nurse you have got to have in the facility has to spend all of her time filling out Medicare and Medicaid forms.

She cannot provide hands-on care. Now, obviously, we need to increase the number of registered nurses, but we cannot allow the least qualified and the least trained members of our society to care for our loved ones. You have got a situation which is explosive. It will only guarantee abuse. So, we cannot rely on those untrained individuals.

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In fairness, we have those same untrained individuals who are working in home care. We try to train them, but there are some significant problems I will allude to in my closing statement.

And, then, too, we must admit that we, as a nation, have not developed our policy with respect to long-term care. In other societies, Mr. Chairman, you knew where you stood. It was respectable and it was predictable, and there is the historian Toibe who used this as an index, and he said that the more sophisticated society, the better they took care of people who were aged and infirmed; he talked about the Chinese and he talked about the ancient Greeks.

The ancient Greeks were preeminent in the sense that if you neglected the duty to care for your parents or your mother and father, and you were found guilty of this offense, you lost the most important thing to a Greek, which was your citizenship.

Now, you can imagine the effect if we removed the citizenship, American U.S. citizenship, if that was revoked from people who abused their elderly and cast them out and said no longer are you going to be a privileged part of the American society. What the effects would be.

Now, we need to fashion some sort of a policy. In other societies, the infirmed were killed outright. And, the third policy that was followed was the neglect and abandonment, but, whichever of those courses the society chose, it was expectable and it was predictable.

I posit to you, Mr. Chairman, that we have got a hypocritical wishy-washy policy in which we tell the elderly we are going to take care of them to the end of their days, but the reality is something more like the abandonment and the neglect which was practiced by the Eskimos and other primitive societies in which the elderly were simply abandoned and left to their own devices.

We need a comprehensive policy with respect to the aged and infirmed. I would like to argue strongly that that policy be based on home care. I have got a vested interest in home health care. As you know, my journey through nursing homes and looking at abuses led me again and again to home health care as a partial solution, believing right down to my marrow that we must provide care for people in their own homes as much as possible, to help them maintain themselves with the maximum of human dignity, and it serves the important social value of keeping families together, and I posit to you there is no more important social value than the preservation of the American family.

So, I am an advocate of home care. It is not a total solution to the problem. We are going to need good nursing homes.

The last point on that subject is the wave is about to hit the beach. We have no idea the force with which it is going to hit us. It is not going to affect just the elderly.

As you know, the demographics are driving it, but the effect is going to be felt by the middle age and the middle class. I make the point that the baby boom generation is the center of gravity in this country. The same people that are trying to support their children through college now are supporting their aged parents, maybe even grandparents as we go to five-generation families, great-great-grandparents, and the burden on the middle age and middle class is massive, and it is going to get worse and you are going to have

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political reactions that come from that, and we will be forced to resort to long-term care if we have not done it by then.

But, in my closing remarks, Mr. Chairman, I would like to sound the alarm about what will happen if we allow the health care financing administration to go through with its plan to cut in a meat-ax approach Federal reimbursement for home health care. They have a new formula which would change the way that home health agencies are reimbursed for care they have already provided, and I am providing something to you which details the problem.

But, the effect of that is going to be to have home health agencies dismiss their more tenured and more seniored employees because they are too costly and hire less expensive personnel, that is to say untrained, literally off the streets, individuals, put them in a position of responsibility, to force them to do what nursing homes have to do now, which is to say that registered nurses will be busy filling out the paperwork and more and more the responsibility will be left in the hands of the untrained aides.

Finally, these new regulations will have the effect of wiping out care in a large part of rural America and put the Federal Government in the anomalous position of paying to establish home health agencies in some parts of rural America, and then making it impossible for them to participate under the Medicare Program.

Now, that is a tragic situation. You, Mr. Chairman, have introduced legislation to block that. I am happy to tell you that, as of this morning, the Senate of the United States has agreed and the Senate Finance Committee has voted to block the implementation of these onerous regulations. I hope the House of Representatives will follow suit, so that I do not have to sit here 2 years from now and predict to you and my prediction would come true that home health care is visited with the same sort of scandal that we have in nursing homes. That has not happened, and as long as I have life in my body, it will not happen in home care.

Thank you, Mr. Chairman.

[The prepared statement of Mr. Halamandaris follows:]

PREPARED STATEMENT OF VAL J. HALAMANDARIS, PRESIDENT, NATIONAL ASSOCIATION FOR HOME CARE

Mr. Chairman and Members of the Committee. It is a pleasure for me to be here with you today as you examine the important topic of physical and financial abuses perpetrated against the elderly.

I enjoyed the years that I spent sitting next to you as your Senior Counsel. You honored me then by letting me work with you, and you honor me now by soliciting my views on this topic.

My involvement with this issue goes back for maybe a quarter of a century. In the early 1960's, I was employed by Senator Frank E. Moss, who was instrumental in the United States Senate Committee on Aging in 1961. Senator Moss became Chairman of the Committee's Subcommittee on Long Term Care, and it was my privilege to assist the Senator in his examination into the problems facing the infirmed aging.

From 1963 through 1965, Senator Moss conducted a series of hearings on nursing home problems which lead to the enactment of legislation know as the Moss Amendments. These amendments provided coverage for nursing home care and home health care in both the Medicare/Medicaid programs and created federal minimum standards for providers who chose to participate in these programs.

From 1969 to 1976, Senator Moss conducted the most comprehensive investigations of nursing home problems ever undertaken. As Counsel for the Committee, I directed this work which included some three dozen hearings in all parts of the nation. These hearings lead to the production of a detailed 12-volume report which I

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wrote entitled "Nursing Home Care in the United States: Failure in Public Policy". Once again, a form of legislation was enacted by the Congress.

In 1977, I summarized this in-depth investigation in a book entitled "Too Old, Too Sick, Too Bad". Shortly after its publication, I moved from the Senate Committee on Aging, and began to serve as Counsel to the House Select Committee on Aging.

As you know, we took another look at nursing home problems in 1980 and 1981. Regretfully, we continued to find serious problems.

In 1980, Ms. Kathy Gardner of the staff suggested that we undertake an investigation of non-institutional abuse of the elderly. I reluctantly agreed to her suggestion naively believing that it would not turn out to be much of a problem. After looking into the matter for more than a year, the evidence we received was conclusive. Elder abuse, that is the abuse of the elderly by their families and loved ones, was a wide spread, yet hidden national scandal. It was a shock to learn that the incidence of elderly abuse is almost as high as child abuse and that only a handful of states had even rudimentary adult protective service laws.

After 5 years with you, and a total of 20 years service in the Congress, I accepted a post as President of the National Association for Home Care. This was a natural transition since home care again and again bloomed as a solution, at least in part, for many of the problems with which I had been grappling. Home health care enjoys a unique reputation within the home care community. In the entire history of the Medicare program, there have only been 7 providers convicted of fraud and abuse in either the Medicare or Medicaid programs. From my point of view, this is 7 too many, but it is extremely favorable as compared to the thousands of providers in other categories who have been convicted. The quality of home health care throughout, remains very high and there is tremendous consumer satisfaction with home health care.

My recurrent nightmare has been that some way, home care would be visited by the same scandals that we have seen in other parts of the health care field, and that I would be called by this Committee to account for these changes. I am happy to tell you that from my detailed investigations, problems in home care are still few and far between; but, the potential for abuse is massive and I ask your help in making sure that these abuses do not permeate the home care field.

To begin with nursing homes, there have been historical problems with the quality of care going back many years. In 1976, the Subcommittee on Aging concluded that 50% of nursing homes in the U.S. were substandard with one or more life threatening conditions. The alleged abuses ran the gamut from poor food, unnecessary tranquilization, negligence, and even deliberate physical abuse. My sense is that the quality of care in nursing homes has improved significantly since the Senate issued its landmark report, but that some problems remain. These problems revolved around the reliance on undertrained personnel, literally, hired off the street, and paid the minimum wage for doing the most difficult job imaginable. In fairness, some of the same people work for home health agencies, and we are beginning to see some signs of problems in home care as well. I will talk more about this problem in a second.

I think we can all agree that we have problems in the field of long-term care. The question is what are the root causes of these problems, and what can we do to correct them.

In our investigation, this Committee, and in the Senate, we identified five root causes of the problem:

1. Physicians Avoid Nursing Homes. It has been a personal crusade for me to try to get physicians interested in long-term care. Their absence from nursing homes led to severe health problems which in many cases could not be handled by the essentially untrained aides left in charge of patients. One answer to the problem is to try to get schools of medicine to place greater emphasis on geriatrics, to require that students spend some of their time in nursing homes prior to graduation and to require nursing homes to employ a medical director with the overall responsibility for the quality of patient care. I feel that we have made some progress in this regard. I would point to Mt. Sinai where Dr. Robert Butler has created the first Department of Geriatrics in a School of Medicine. I would also commend Chairman Pepper for funding a Chair in Geriatrics at Florida State University in conjunction with the Mildred and Claude Pepper Library.

2. Financial incentives in the payment of nursing homes have been misaligned; they work against the provision of this quality of services. Under so-called flat fee systems, nursing homes have an incentive to cut back on needed care to make a profit. Under the cost-based retrospective reimbursement, the incentive is to turn up reimbursable costs. Neither one of these systems rewards homes for excellent performance or provides them with the incentive to make quality important.

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Indeed, the major message nursing homes are getting from the government now is cut costs.

3. The enforcement systems in the Medicaid program simply did not work. We found Medicare, for the limited number of patients who could quality for it, did somewhat better. Medicaid, however, is a bifurcated program in which both the states and Federal government for years have each contended the other has the primary responsibility for preserving quality of care. The statute makes both responsible but the Federal government has preeminent responsibility.

4. Historically, nursing homes have been criticized for their reliance on untrained and unlicensed personnel. Significant inroads have been made to try to get more trained personnel. And then, too, nursing homes have benefited from DRGs by absorbing many of the 100,000 people who recently lost their jobs in hospitals. Still, Medicare and Medicaid regulations have been applied in a paradoxical way. The most trained individuals, registered nurses, have been kept busy filling out paperwork while the hands-on care has been relegated to the least trained aides. Turnover rates have historically been about 75% a year. Little wonder that some nursing homes are going to have problems under these circumstances.

5. Finally, the United States has yet to promulgate its national policy on long-term care. In other societies the sick and elderly knew where they stood. The policy was predictable. It was expectable. Essentially, there have been three options. First, the infirm elderly were abandoned or neglected—we all think of the Eskimos who were left out on the ice flow. In other societies they were killed. In more enlightened societies, the infirm elderly were cared for until the end of their days.

The U.S. has yet to decide on its policy. We speak of care and concern and yet the reality most closely resembles abandonment and neglect practiced by more primitive societies.

I have grappled for some time with the question of why we haven't formulated a national policy in the area of long-term care. We have had two White House Conferences and a dozen reports from the Congress calling upon us to do so and articulating the broad outlines of such policy and yet nothing has happened. You have only to look at some of your previous reports where we recommended that day care, and comprehensive home programs be made available. Once again, we have made some progress because of amendments which this Committee pushed into law in 1981, but we haven't seen the dramatic shift for which we had asked. What we had suggested is a policy in which home care was the norm and institutional placement the exception of last resort. That goal is far from reality today.

What I see on the horizon is a devastating problem. As we have set back mortality, there has been a significant increase in morbidity among the survivors. More and more people are living longer and struggling with chronic disabilities. The government estimates that there are about 5.5 million Americans today that are going without the home care and long-term care services that they need. This number can only increase in the future. We are going to need more of the finest quality nursing homes to meet the demand; we will need to expand home care services and authorize other options such as day care and respite care.

My conclusion for why we have not as yet formulated a national policy with respect to long-term care is that as a nation, we don't seem to be very good at planning ahead. Time and time again, the Congress reacts with stopgap measures to deal with ongoing problems. This is all the more evident in the current environment when there is more and more competition and fewer and fewer dollars. What I am suggesting is that the problem of who is going to care for our elders looms as the most important social problem for the balance of the 20th century.

I have argued that the baby-boom generation is the center of gravity of this country. I see many of these young people approaching middle age trying to pay for their children's college education at the same time when they are being asked to assume responsibility for aged parents or grandparents. Since five generation families are more common now, they may even be accepting financial responsibility for great grandparents as well. Little wonder they call this group the "sandwich generation."

I believe that the pressure from demographics and increased longevity will force us to respond and hammer out a policy in the next five years if we have not done so before then. The support from the middle aged and middle class which increasingly will shoulder the burden of paying for what Americans buy in their national budget virtually guarantees that such a policy will be enacted at the Federal level. Undoubtedly, we will have some partnership involving private insurance and the states; but, only the Federal government has the resources to deal with a problem as massive as long-term care.

Mr. Chairman, the solutions which I propose are the correlatives of the problems. If we suffer from the lack of a comprehensive problem in long-term care, the answer

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is to formulate one. If physicians avoid nursing homes, the answer is to find ways to get them involved. If financial incentives are misaligned, the answer is to properly align them so that dollars paid encourage excellent care. If the problem is the enforcement system, then reforms need to be instituted. A stronger patients' bill of rights is one solution. And, if the problem is the reliance on untrained personnel, then we must find ways to help train nursing home employees.

In the home health context, I believe that government action, if left unchanged, will cause the first major scandals in home care. The potential is there. I ask your help in making sure that it does not happen. Both examples that I will mention relate to consequences of the government's efforts to save money.

First, you should know that some states have attempted to save money in the provision of home care. Rather than subcontracting through licensed home health agencies, they have contracted directly with so-called individual providers. What I am talking about are unlicensed "shoe box" operations usually involving an owner and a list of nurses or aides that he has on a roster. The owners of these "shoe box" operations do not provide any training or supervision of their employees. Under these circumstances abuses will occur. In another variation, states hire aides directly and assign them to care for needy seniors. Where there is adequate supervision and training, I have no problems but quite often, these elements are missing. Some states even go so far as to maintain that these individuals are independent contractors, and not employees of the state. They maintain the fiction that the elderly client is the employer, when in fact, the state has all the control, assigns workers and pays the bill.

In many instances, states are actually cheating the employees by refusing to pay FICA, unemployment compensation, and other benefits. One reason that states have taken this attitude is to limit themselves from legal liability should some client be abused. There have been such cases and you will hear more about them. Unfortunately, the public cannot distinguish in its mind between the operations of such "shoe-box" providers and reputable home care agencies.

The other example to which I refer involves HCFA's step by step dismantling of the Medicare home care benefit. It's a subject for another hearing. One you might want to hold sometime. Time and time again, HCFA has proposed cuts in the Medicare entitlement which are affected in the guise of new guidelines to insurance companies that pay Medicare claims. Over the past two years, more than two dozen of these initiatives have been directed at the home care industry. Many of them have been repelled thanks to you and the Congress, but others have not. There is today pending within the Congress legislation to block HCFA's implementation of new methodology for computing reimbursement to home health agencies which participate in Medicare. If these regulations are put into effect, the results for beneficiaries will be devastating. What will happen is that fewer home health services will be available particularly in rural areas and the quality of care will be reduced as agencies are put in the position of having to fire their tenured and therefore, most costly employees.

Mr. Chairman, you and many of the Members of the Committee have joined in sponsoring legislation to repeal these onerous new formulaes which will create financial incentives for poor care in the home care field. (H.R. 3202) I am happy to tell you that the Senate has voted to accept this legislation (S. 1450) and I am hopeful that the House will follow suit. Rather than elaborate further, Mr. Chairman, I ask unanimous consent that the appendix to my statement be entered into the record.

In short, Mr. Chairman, we have a sizeable problem here. We have looked at it from the point of fraud and abuse which occurs in institutions. We have found that abuses are perpetrated in private homes by relatives. Moreover, there is ample evidence of abuse by so-called individual providers who masquerade as reputable home health agencies. The legislation which you have introduced with Congresswoman Mary Rose Oakar is a good start. I endorse it wholeheartedly. Other measures are clearly needed. Your vigilance I believe is crucial. We can make great strides as long as policymakers at both the state and Federal level know that you are watching. I thank God for this Committee and its sister in the Senate. I think I know something of how much poorer the life of the elderly would be without you. I commend you for the excellent work that you do on their behalf.

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ANALYSIS OF EFFECTS OF THE NEW MEDICARE HOME HEALTH COST LIMITS ON BENEFICIARIES AND PROVIDERS OF SERVICE

I. ISSUE

On July 5, 1985, HCFA published final rules effective July 1, 1985 which significantly reduced Medicare payments to beneficiaries of home health services. They did so even though numerous Members of Congress had asked them not to finalize any regulations until after Congress had completed its action on the FY 1986 Budget Reconciliation Act. Among those who wrote were Senator Dave Durenberger, Chairman of the Health Subcommittee of the Senate Finance Committee, and Congressman John Duncan, Ranking Republican on the House Ways and Means Committee.

A. Present Law

In 1981 Congress enacted Public Law 97-35 which established national cost limits for home health agencies. The costs of all agencies accordingly were arrayed and a line was drawn at the 75th percentile as required by the Congress. No agency was reimbursed above the 75th percentile. In other words, costs above this limit were not reimbursed.

This law meant that many agencies incurred costs in providing care for Medicare beneficiaries for which they were not reimbursed. But what made the system livable was that agencies were allowed to aggregate (average out) the costs from among the various kinds of services which they were mandated to offer by Medicare (i.e., skilled nursing care, physical therapy, speech therapy, occupational therapy, medical social services and home health aides). It also was the aggregate agency cost that was arrayed to establish the 75th percentile and agencies were judged on meeting the limit in the aggregate as well -- not on a discipline by discipline basis.

B. The Change Made By HCFA

HCFA has in effect changed the statute through the July 5th regulations. First, instead of the present test of 75 percent of the agency costs being the upper limit of reimbursable costs, they have substituted 120 percent of the mean per visit. Second, the regulations throw out the highest and lowest 5 percent of costs (the so-called "outlier") which serves to lower the mean. Third, the regulations call for automatic reduction to 115 and 112 percent of the mean in the two subsequent years respectively. Fourth, they have removed from home health agencies the right to aggregate costs.

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II. PROBLEMS WITH METHODOLOGY

(1) **Out of Date Data**

The data base on which the new cost limits are calculated is nearly three years old and contains no effective mechanism to update cost implications caused by the changing nature of services and the client population over the last 3 years. Specifically, the data predates the DRG payment system for hospitals which has resulted in much higher costs for home health agencies because they have been called upon to care for greater numbers of patients with intensive medical needs.

(2) **"Percent of the Mean" an Unsound Measure**

There is no evidence of any pilot test or other trial evidence to justify a 120 percent of the mean measure as opposed to the 75th percentile approach or applying different percent of the mean measures to each discipline. There is no evidence that the Congressionally-mandated 75th percentile promotes inefficiency or unjustly rewards agencies above normal and customary operating costs. Finally, without some pilot test of the percent of the mean approach and updated data, there is no valid and reliable basis for imposing now the 115 percent of the mean and 112 percent of the mean measures for July 1, 1986 and July 1, 1987, respectively.

(3) **Elimination of Aggregation Not Feasible**

The elimination of the aggregation method is not feasible at this time because it is the only method which effectively allows agencies to deal with: variations in the supply, demand and cost of professionals (particularly physical, speech, and occupational therapists and medical social workers) needed to deliver Medicare-mandated services; variations in the nature of the client population, particularly where there are clients with multiple diagnoses requiring multiple services and/or "high-tech" care; variations in the size of agencies' service areas, particularly rural-based agencies. Furthermore, the use of aggregation is fiscally sound in that it operates as a capitated limit which the agencies must operate under.

III. EFFECT OF THE NEW REGULATIONS

In our judgment, the new regulations would result in the following:

(1) The level of home health services which Congress has mandated by statute for Medicare beneficiaries will be significantly reduced at a time when the demand for such services is sharply increasing. The reason for the increase is the enactment of a prospective payment (DRG) system for hospitals which creates incentives to move patients from hospitals into home care.

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(2) Agencies will drop out of Medicare. Hundreds of agencies will go bankrupt.

(3) Agencies will no longer offer important but costly services, such as physical therapy for which they will not be adequately reimbursed.

(4) New agencies and small agencies will be hardest hit, regardless of how efficient they are. These agencies tend to have relatively higher costs and will be at an economic disadvantage. Older agencies will suffer to the extent they have tenured and, therefore, higher paid staff. The incentive will be to replace them with new staff members with lower salary demands. This will have serious consequences as far as the quality of home care services.

(5) Agencies in rural areas will be devastated. Such agencies have significantly higher costs as they try to deliver services. Obviously, transportation expenses are much higher in these agencies which must often send their employees great distances to care for clients who would otherwise go without health care altogether. In addition, therapists and social workers are often scarce and therefore more costly in rural areas. This increases the per visit length and cost. The policy of undermining rural home health agencies puts the Federal government in the incongruous position of spending millions of dollars in grants and loans to help create such agencies with one government program (the Public Health Service) and making it virtually impossible for them to serve clients through another program.

(6) Agencies which provide so-called "high-tech" care such as the care of ventilator-dependent persons, IV chemotherapy, or IV nutritional therapy will find it increasingly harder to do so. These services have relatively high costs and will be discouraged under the new reimbursement system. Ironically, these are among the very services which make it possible to move patients from hospitals into less intensive settings.

(7) Agencies will be forced to be selective about which Medicare patients they take. Agencies may be reluctant to accept so called "heavy care" patients (such as stroke victims), whose cost per case is relatively high, and indigents.

(8) The level of paperwork required by the new system will increase dramatically, leading to higher Medicare costs; ironically, such costs will have no relation to the provision of Medicare care.

(9) Significantly, the proposal would either eliminate or sharply reduce care. The Visiting Nurse Service of New York, for example, gave $2.5 million in free care to indigents last year. The money was raised through private contributions. Such contributions will be needed to compensate the agency for Medicare losses in the future.

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IV. THERE IS A GOOD CASE THAT CONGRESS SHOULD INCREASE RATHER THAN REDUCE THE MEDICARE HOME HEALTH ENTITLEMENT

There are numerous recent studies which indicate that the need for home care and long-term care is serious and becoming more acute. Expenditures for home health care are still a tiny part (2% percent) of Medicare expenditures. Examples of credible sources citing the need to expand home care:

(1) The House Aging Committee, Subcommittee on Long-Term Care in its December 1984 report concluded:

> There is a massive unmet need for home care services. The most conservative and hardest data indicate at least 5.5 million people need home health services. About 2.1 million of these people need the kind of assistance which will result in their placement in a nursing home if home care is not provided — namely assistance in toileting, dressing and washing, cooking, shopping and going out.
>
> Congress should consider a general extension of the home health benefit targeted to those individuals most likely to be placed in nursing homes absent assistance at home.

(2) The Heritage Foundation in their December 1984 report concluded:

> The keystone of long-term health care policy should be a comprehensive program fostering home services.

(3) The National Center of Health Statistics said in 1984 that 4.9 million Americans are going without the home care services they need.

(4) The Senate Labor and Human Resources Committee conducted hearings June 12, 1985 on the need to provide greater Medicaid coverage for pediatric home care.

(5) Senator John Heinz, Chairman of the Senate Aging Committee, in February 1985 issued a preliminary report by the U.S. General Accounting Office on the effect of DRGs which demonstrated that higher numbers of patients with more acute illness were being pushed into home care. Senator Heinz has introduced legislation to broaden the current limited coverage for home care in the Medicare statute. The Task Force on the Rural Elderly of the House Aging Committee made similar findings in February 1985.

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V. SUGGESTED ACTION

(1) There is a good case that home health agencies should be given appropriate legislative relief to cope with the increased number of patients with more acute medical needs being discharged earlier from hospitals as a result of DRGs. Such patients inevitably are more costly. S. 778 would accomplish this objective.

(2) If the Congress believes that home health agencies should be included in a general freeze with all Medicare providers because of the need to reduce the deficit, then Congress should take steps to block the impact of the proposed new cost limit methodology by inserting legislative language in the FY 1986 Reconciliation Act which holds home health reimbursements at the same level and mandates use of the same methodology as was in effect under the schedule of cost limits prior to July 1, 1985. Senator John Heinz, Chairman of the Senate Aging Committee has introduced S. 1450 which would allow this result.

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Mr. PEPPER. Thank you very much, Mr. Halamandaris, for your usual good statement.

Next is Mr. Richard Mahan, executive director, Commission on California State Government Organization and Economy, known as the Little Hoover Commission, Sacramento.

Mr. MAHAN, we are happy to have you here.

STATEMENT OF RICHARD MAHAN, EXECUTIVE DIRECTOR, COMMISSION ON CALIFORNIA STATE GOVERNMENT ORGANIZATION AND ECONOMY, "LITTLE HOOVER COMMISSION," SACRAMENTO, CA

Mr. MAHAN. Thank you, Mr. Chairman. It is a pleasure to be here.

For the record, my name is Richard Mahan, and I am here on behalf of Chairman Nathan Shapell and the members of our commission. For the last 2 years, we have conducted extensive investigations, detailed studies, and literally waged a campaign for enactment of major reforms in California. Those reforms are now known as the Nursing Home Patient's Protection Act of 1985, which took effect in March of this year.

I am not going to go into the litany of abuses that we observed during the course of our work. I think you have had plenty of examples of that today. I will just add to it by stating that or describing a response that the chairman of our commission, Mr. Shapell, who is a survivor of the Auschwitz concentration camp, stated, upon making a surprise visit to a facility, and we made several in which tears came to his eyes.

He said, "I never thought I would see conditions like this in America."

What I would like to do is touch upon a sample of areas that our reform legislation covered and through that, I think also offer some recommendations on what I believe needs to be done at the Federal level.

Some of the things that we dealt with, we made great strides, but we ran into some roadblocks, partly because of Federal statute.

First of all, there has been a lot discussed today about fines. Our legislation resulted in substantial increases in fines. When we started our work, if there was a death in a facility, the maximum fine that could be levied was $5,000. As of right now, that fine against the facility is—can be a maximum of $25,000.

Inspections are a critical area. We made recommendations that they be segmented rather than once a year. Unfortunately, the State of California was unable to get waivers from the Department of Health and Human Services to, on a pilot basis, conduct segmented surveys.

The problem we have today is that surveyors go into a facility and they get one snapshot of conditions and you have heard testimony about not only that there are tipoffs, but that these inspections, because of the nature of the cycle, can be highly predictable, even without a tipoff.

The reality is that there is about a 90- to 120-day period that a facility knows they are going to be inspected, and they can pretty well guess almost down to the week or the day of the week when

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they are going to come in. We had cases in northern California where linen, food, and staff were brought in because they knew an inspection was coming.

One major conclusion we reached is that there is a terrific need for more sets of eyes. You cannot have enough inspectors, enough evaluators going out and going to the facilities to identify all the problems. There needs to be changes to the system to provide for a more educated consumer.

We enacted legislation to create a consumer information system which will provide an 800 toll-free number to the public to call and get a complete report on the status of a facility, what its enforcement record is, what citations are against it, and what they were for, as well as providing important information to the consumer on the types of services that are provided, whether they focus on particular religious groups, things of this sort.

Now, there has also been discussion today about staff, and the adequacy of training. Your chart up there indicates that the medical doctors only spend about 30 seconds a day of time giving care. The reality of what we found is frequently, if not most of the time, that 30 seconds is provided over the telephone, by call-ins to conduct their required inspections and examinations of the residents.

But, the reality is that that is not care, that is just fulfilling a requirement. We believe and we promoted an expansion of geriatric nurse practitioners in facilities. This is something that, while there is a very small supply today of these. is growing and government, particularly the Federal Government, needs to get behind. If they were in the facilities providing care and calling in doctors on an as-needed basis, rather than having a set requirement of there will be a medical physician who will provide an examination on a periodic basis, we think it would improve care significantly.

One of the areas that we made major changes that I think need to be spread to the whole country and the Federal Government could be a leader in this is the area of appeal rights for the residents.

All the cards were held by the industry when we went in and began our work. If a facility was cited for a violation, it could go through a process that basically caused the citation to be thrown out. They could appeal it to the district administrator of the licensing office, and they had all the information. They would bring in their attorneys. The individuals who were the victims, the family members, never had an opportunity to be present during those administrative hearings.

Furthermore, all a facility had to do was appeal to the superior court and because the dollars involved were so small in terms of fines, having been so low, that the State would never continue the case because it would cost them more to prosecute than the money they were going to recover.

Unfortunately, it was a cost-benefit decision that did great disservice to the residents of the facility. The whole system has changed now. We allow the appeals to go to the court of competent jurisdiction relating to the amount of money that is involved in the fines and a complete set of statutes are outlined on who can participate and shall participate in the appeals that are done with the district administrator.

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One of the most immoral events that occurred in California and I know occurs across this country is what is known as Medicaid evictions. People are literally being placed on the doorsteps, sometimes at 2 and 3 o'clock in the morning, after maybe having been in a facility for 10 to 15 years and having exhausted hundreds of thousands of dollars of their own personal funds. But when the resident runs out of money and converts to Medicaid, the facility, not wanting to have to take the cut in revenue, evicts the individual.

We passed statutes that will prohibit that. We also established a 7-day bed hold, which will help prevent a facility from using an indirect form of eviction accomplished through transferring a resident to an acute care hospital, usually for a bogus reason, and by the time the individual is ready to come back, their bed is gone. That will be less of an occurrence in California now.

I think ultimately you do have to talk about dollars and the whole method of financing and reimbursing nursing homes, and I think an important point that has been made here today is what type of incentives exist. In California, there is a flat rate system. That does not provide incentives, except in the form of taking the patient that is the healthiest and thereby requiring the least amount of care possible.

We do not talk about this, but what happens is all we ever do is deal with maintenance. We never deal with trying to help a patient, a resident, become better. I think there needs to be incentives built into the system so that the facilities are not just providing maintenance care, but are actually making the individual better.

There is certainly enough pilot projects on line as notable that demonstrate that that can and has happened.

Ultimately, it comes down to a matter of will, though. There has to be the will. We were successful in our campaign because we involved 150 different organizations across California. We collected over 100,000 signatures for enactment of the nursing home patient protection act. We involved elected officials. We filled hearing rooms and we did one hell of an editorial circulation to editorial boards across the State, getting their support.

You have to look at this like you are running for office. If you are going to get the changes enacted, whether it be through Congress or the individual States, it has to be a campaign. The elected officials have to be held accountable, and it has to be done in a way that the industry, with their powerful money and their powerful lobbyists, cannot knock off the individual pieces of legislation. That has been our problem for over 10 years.

In closing, I just want to note one other aspect of our work, and that is that we did major work concurrent with our work in nursing homes on board and care homes or community residential care facilities, as they are known in California. We found that the conditions in those facilities make conditions in nursing homes look excellent.

They are in the embryionic stage compared to the problems that we are now dealing with in nursing homes, and the quality of care and the sophistication of care being provided. The realities are, Mr. Chairman, that as DRG's continue to be implemented and we see the effects of all the other societal evolutionary facts that are af-

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fecting the aging population, we are going to find that those community residential care facilities are going to become the dumping ground even more than they are today, and those facilities, while they are not licensed to provide medical care, are, in fact, providing medical care today, and they do not have any capability.

The people that are being hired in nursing homes as aides have far greater capability and intelligence in many respects than the people operating community care facilities. We found cases of decubitous and gangrene in community care facilities that paralleled the pictures you have seen here today, and the stories you have heard.

It is a time bomb that is ticking and it has to be dealt with and dealt with by the Federal Government.

Mr. PEPPER. Let me interrupt you there. Is that—are you talking about local proprietors who own a building and they take in elderly people to live there?

Mr. MAHAN. It can be. In California, it ranges from an individual who in their own private residence receives a license and takes in one, two, six individuals, all the way up to facilities which are considered licensed as residential community care facilities that have 560 beds.

So, there is quite a range. In California, there are 22,000 of these facilities serving the elderly, the mentally disabled, the developmentally disabled. California only has a total of about 300 staff trying to monitor those facilities, as well as monitoring another 50,000 day care centers.

It is a ridiculous challenge. The other problem that is evolving——

Mr. PEPPER. Excuse me. A little while ago, one evening, I addressed that group. They have a national association. I was not aware of their existence, but I got an invitation to speak to them, and I did.

They told me that they offer one way of providing shelter for the American people. My staff here and I have worked very hard over the years to try to provide shelter for the homeless people that do not have any place to stay, and this organization they said they were beginning to do that.

We knew that with the attitude of the present administration and the condition of the national budget and deficits, we were not likely to get any large appropriations for money to build buildings that would be shelters. There would only be homes for the elderly in these more or less boarding house type of facilities.

So, I thought well, maybe it has some possibility because you—instead of appropriating the money from Washington and building a whole lot of buildings all over the country, these people come up with buildings in their own communities.

The entrepreneurs are the local people. Then, the complaint that they made was that when an elderly person lived in a nursing home or some public facility, or private home, they were getting, for example, food stamps and the like, but they lost all those benefits when they moved into one of these board and care facilities. They wanted us to see if we could not prevent the loss of those Federal benefits that they would receive if they were in their own homes and the like.

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Now, it is obvious, however, that there has to be regulators for these places, and they will have to be inspected and carefully examined.

Do you think that they are in the national interests, that type of facility, if they are properly regulated and the like?

Mr. MAHAN. Well, there is no question that there is a need, Mr. Chairman. I think the issue is what services they are going to provide, what type of care they are going to provide, and how is it going to be regulated.

As originally conceived in California, it was a system that was primarily providing a very limited level of supervision, care, and housing and meals, and in certain cases, distributing prescribed drugs.

What has happened is, again going back to my point about the DRG's and the effects it is having as well as the incentives that exist in nursing homes, as the more severe cases are pushed out of the acute care hospitals and into nursing homes, the nursing homes are trying to make sure that they have got the healthiest people possible to keep their costs down. We have forced down into these facilities individuals that require a greater level of care than these facilities are qualified to provide.

Now, in California, how we have responded to that and in the next couple of weeks, Governor Deukmajian will be signing a Community Residential Care Act for the Elderly, that will set up a system that is tailored to the elderly and it will provide for the development of levels of care, for the first time, an acknowledgment that some very limited levels of medical care will be provided in these facilities, and it will be regulated.

Time will only tell how successful this is, but it is accepting the reality of what the conditions are rather than——

Mr. PEPPER. Clarify in my mind one thing. My understanding is that nursing homes do not provide medical care for their patients, that the individual is supposed to provide his or her own medical care, is that correct?

Mr. MAHAN. The community residential care facility is not supposed to be providing medical care. Of course, skilled nursing facilities provide——

Mr. PEPPER. They do provide room and board and a place to sit down and a few maybe minor recreational activities.

Mr. MAHAN. Well, the skilled nursing facilities——

Mr. PEPPER. They do not provide—is that the consensus of the panel, that nursing homes generally do not provide medical care to their patients? That is true?

Mr. HARTIGAN. Not nursing homes, Mr. Chairman. I believe he is talking about a different type of facility. In the community where there is a much lower level of care provided, the distinction in Illinois is with prescription medicine and provision of those drugs and nursing care that is traditionally found in a nursing home.

Mr. PEPPER. Is that provided by the State?

Mr. HARTIGAN. Well, it is—that is covered in the licensure within the traditional nursing home intermediate care, skilled care, that type of thing.

What I believe is being referred to here is more of a home setting where there might be a single individual or six people or some-

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thing like that, and that—I believe you said in California, there are 22,000 of those involved.

When I was referring to unlicensed homes in my testimony, those in Illinois are dumping grounds. After they have taken everything they can get from people in the way of benefits and what have you, they dump them into those places. They are not licensed at all.

So, we have got one step worse than the situation——

Mr. MAHAN. Unfortunately, California has the one step worse also. Except in the community residential care facilities, which are regulated on a limited basis, the phenomenon we are now experiencing—and we have legislation on the Governor's desk that will help to further enforce it—people that have been previously licensed are giving up their licenses and operating in an unlicensed fashion because they do not want to have to deal with Government regulation.

They know that the Government enforcement structure is never going to find them, and it rarely does. So, we have taken action to provide legal definitions to clarify licensure as well as providing some enforcement mechanisms against an unlicensed facility because the problem is if you are not licensed, the State has no authority to fine you or take action against you. So, that is how being unlicensed——

Mr. PEPPER. And, what you gentlemen have just said shows the desperate effort that is being made to try to provide adequate facilities for the elderly people of this country. It certainly should challenge not only the States, but the Government of this country to provide a meaningful program for—yes, Dr. Jacks?

Ms. JACKS. I would like to share with you that in Florida, we have had some success in looking at the whole continuum of care needed by the elderly, beginning with a Community Care for the Elderly Program. Through that program, the State, originally using State general revenue and later using some Older Americans Act funds, provides many services to help older people remain in their own homes.

The second level is what we call an adult congregate living facility [ACLF]. These are facilities licensed by the State and which provide care for people who need board, room, personal care, and supervision. These facilities are not allowed to give nursing care. If a resident becomes ill, that resident can contract for nursing care, but only for a short, temporary period of time. An ACLF is not for people who need continuous nursing care.

The third level of care licensed by the State is the skilled nursing home. However, we have found that there may be a gap between the ACLF and the nursing home. There are people who do not need nursing home care, but who need more care than can be provided in an ACLF. We think a home for special services may meet this need. As a result of our questioning, we have two projects going on Florida to test if we can identify another level of care that would fill this gap.

We also have adult foster homes which provide a family setting for one to three persons. These homes are approved by the Program Office of Aging and Adult Services of the Department of Health and Rehabilitative Services.

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Mr. PEPPER. Thank you, Doctor.

Mr. Mahan, you go ahead.

Mr. MAHAN. Just a closing comment, Mr. Chairman, and that is that we found one of the things that was the most successful was the passing of a statute that requires that the state department of health services issue press releases announcing to the public what the results of inspections when a certain level of severity of violation was discovered.

That has probably had a terrific effect in terms of educating people to steer clear of certain facilities as well as putting those facilities on notice and causing them, because they know people are looking at them, to try to clean up their act.

I think if you seriously want to have some effect, if you could get every Member of Congress to have a staff person in their district office make a surprise visit on a nursing home once a week and issue a press release on what you found, whether it be good or bad, you would probably find a substantial improvement in the quality of care being given because, again, it would create more sets of eyes and the public visibility.

The reality is these people have been forgotten. The communities, the relatives are not paying attention to them, and, so, the facilities can get away with the type of care that they provide. We have got to create a situation where the visibility is focused on the conditions and on those facilities and that is why I say a campaign has to be waged——

Mr. PEPPER. Is it not a fact that the Federal Government pays the cost of inspection that is carried out by the States?

Mr. MAHAN. The Federal Government reimburses the State for the inspections as it relates to certification for Medicare purposes. That is correct. But, our view of it is that as of right now, the individuals that live in these facilities, in essence, have one parent, and that being the state, you know. They need both a mother and a father. They need the Federal Government to take a far more active role to make sure that there is consistentcy throughout the States and the States are fulfilling their jobs.

Mr. PEPPER. Well, now, summarize what you would recommend that be done.

Mr. MAHAN. Well, as I just noted, the State needs to have much greater guidance from the Federal Government. States across this country, so that there are minimum levels of an enforcement system relating to fines, relating to bed holds, relating to a myriad of issues that we dealt with in our reform legislation.

California needed it, but if California needed it, I would be willing to bet at least 40 other States need it even more.

I think if you could do anything to cause change to the inspection process and the current Federal requirements that it be a once a year event and it become a segmented process so the inspectors are in there more frequently, on a quarterly basis, that, again, we are going to have a more continuous picture of how the facility really is, what conditions exist, plus it is going to cause them to know that people are looking at them all the time.

I already mentioned fines are a necessary step. I think that it is making a major difference in California, that we have created a fine structure now that really is somewhat commensurate with the

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severity of the problem. I think that the Federal Government must take the lead and go beyond where what we were able to accomplish in dealing with the evictions at the time of conversion from private funds to Medicaid funds, and, finally, I think that it would be wonderful if the Federal Government could promote the systems throughout this country in every State, such as we are now developing in California, and that is a consumer information system, where the public has an 800 toll-free line access to information on facilities in their areas and what their inspection process is.

The best consumer is an informed consumer, and as of right now, the consumer is working from ignorance.

Thank you very much.

[The prepared statement of Mr. Mahan follows:]

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PREPARED STATEMENT OF RICHARD MAHAN, EXECUTIVE DIRECTOR, COMMISSION ON CALIFORNIA STATE GOVERNMENT ORGANIZATION AND ECONOMY, SACRAMENTO, CA

Good morning Mr. Chairman and members. My name is Richard Mahan and I am the Executive Director of the Commission on California State Government Organization and Economy, also known as the "Little Hoover Commission." I am pleased and honored to be here to speak today on our Commission's past investigations and studies of conditions in California's nursing homes and community residential care facilities, and our accomplishments in bringing about new protections for our State's institutionalized elderly.

Each day more than 160,000 Californians call one of the 1,170 nursing facilities or 3,200 residential care facilities for the elderly in our State their home. Most of these people are very old and very frail. For all but a small percentage of these people, that nursing home or community care facility is likely to be their last home.

In the words of our Commission Chairman, these are California's "forgotten people." Some estimate that as many as 75 percent of the residents of these facilities have no visitors during an average month. Many have outlived their relatives while others have simply been deserted by family, friends, and the community in which they have spent their entire life. Because these people are frail and alone, they are particularly vulnerable to the abuse and exploitation that occurs in some very bad facilities.

For more than a decade, the Little Hoover Commission has had a continuing interest in long-term care issues. Since the early 1970's, our Commission has conducted numerous public hearings on conditions in these facilities as well as making selective surprise visits to facilities. Through these early years of our work, we offered recommendations for improvements of certain aspects of the regulatory process overseeing these facilities.

Although many of these recommendations were implemented, the most severe cases of abuse never went away. Quite candidly, the licensing and enforcement system had never been strong enough to eliminate these horrible cases.

Based upon informal reports we received, in 1982 we decided to reopen our work. This time, though, we initiated two comprehensive, parallel studies. The first addressed over 18 separate policy and operational issue areas regarding the State's system to license, monitor, and enforce conditions in nursing homes. The second study evaluated the whole system for delivering community residential care services, and the inadequacies of the State licensing and enforcement efforts which oversee those facilities.

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The recommendations emanating from these two studies were translated into 40 different pieces of legislation over a two year period, the vast majority of which have been enacted or will be signed into law in the next two weeks. Collectively, they produce historical reforms to our licensing and overall regulation of these facilities. Other states and even two foreign countries are currently reviewing our report and the legislation as possible models for reform to their systems.

At this point, I would like to divide my testimony into two parts and address separately our work on these two critical areas of care for our elderly. First, I'll discuss our work investigating nursing homes.

During an October 1982 public hearing, our Commission heard testimony from over 20 witnesses describing cases of neglect, physical and sexual abuse, and the frustration with dealing with the "bureaucracy of care." This testimony validated other testimony gathered by legislative committees during the prior year. And yet, little or nothing was being done to reform the system and ensure that the health and safety of our frail elderly were being protected. Although reports had been issued and legislation introduced, the nursing home industry was always successful in defeating any meaningful measure. The result -- the licensing, monitoring, and enforcement system had never become strong enough to do battle with the very bad facilities. In fact, the deck was stacked against the government.

Our Commission believed that much more could be done to protect the 105,000 frail and elderly individuals living in California's nursing homes. In response to these special problems, the Commission pledged to go beyond just writing another report to take up space on a bookshelf. Specifically, the Commission appointed a Blue Ribbon Advisory Committee chaired by California's Lieutenant Governor, Leo McCarthy, and represented by the Chairs of the legislative policy committees, the State Department of Health Services, the legal profession, consumer groups, the State Ombudsman, academia, the medical profession, and the nursing home industry itself.

The advisory committee invested hundreds of hours collecting data on almost 800 nursing homes, contacting scores of individuals, analyzing a broad range of issues, and developing over 80 detailed recommendations for reforms.

Before summarizing the major findings and recommendations enacted, let me briefly describe a few examples of abuses that we found to be all to commonplace.

- In one facility in Crescent City, a nursing home had patients that showed signs of abuse and who had several bedsores. This facility had only one washcloth for every nine patients.

- Residents are frequently subjected to retaliation if they report complaints. In one facility, a woman in her eighties voiced a complaint to a relative and received a black eye from the orderly. She complained again only to result in her second eye being blackened.

- Beatings are common forms of abuse. Until our reforms were enacted, cases would frequently receive only a $50 to $250 fine.

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- Robberies of residents' personal belongings also occur in these facilities. In one facility that members of our Commission visited, we found radios and TV's literally chained to the beds because so many items had been stolen.

- Drugging residents so they won't complain or require attention is a common practice in the very bad facilities.

- Perhaps one of the cruelest injustices involves the eviction of a resident who has exhausted his/her personal funds and is converting to Medi-Cal. We heard story after story about residents literally placed on the front doorstep at midnight of the last day of private payment to await being picked-up by a relative.

- More subtle ways of removing "undesirable" residents also occur. Facilities frequently send them to an acute care hospital under a bogus malady and then give away their bed to a new resident who is usually less frail, and a private paying patient.

- Patient's rights have been frequently violated without any available recourse by State evaluators. For example, residents are frequently dressed in clothes that are not theirs; residents are also denied privacy with visitors. In the past, cases such as these were not subject to any fines although these situations violate the resident's personal rights.

These examples are but a sample of the abuses we either saw first hand, or received testimony on. The members of our Commission, and particularly our Chairman who is a survivor of Auschwitz, did not rest with issuing a 400-page report on these problems. We immediately began a campaign for enactment of the Nursing Home Patient's Protection Act, a package of 16 bills to enact the vast majority of our more than 80 recommendations. After a long and, at times, heated battle with the industry, we saw all but a handful of the measures enacted. Below is a summary of the major reforms which have been in effect since March 1985.

FINDINGS	REFORMS OUTLINED IN NURSING HOME LEGISLATION
Appeals: Actions, Reversals, Inequities and Delays	
The Commission found that complainants have no statutory right of appeal should they be dissatisfied with the department's determination as to the issuance of or level of a citation and recommended the Legislature adopt a formalized appeal procedure with notice to complainants of the opportunity to appeal.	Establishes a formalized appeal procedure for complainants dissatisfied with determination of LCD whether to issue a citation or in the amount or level of fine. Complainants may first appeal to the District Administrator. DA must respond to complainant and licensee within 10 working days with notification to the licensee of his/her right to appeal to the Chief

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	of Licensing and Certification Division of DHS. The Chief of the LCD has 30 days to review the facts and make a determination and to notify the complainant.
Citation review conferences lack balance because complainants have no right to participate. By the end of the first quarter in 1983, figures showed that review conferences upheld only 12% of the violations heard, modified 77%, and dismissed 11%, and fines were reduced by well over half.	When a citation is a result of a complaint, or when a specific person is affected and the citation results from the annual survey, the following persons may attend: 1) Complainant and his or her designated representative; 2) A personal health care provider; 3) A personal attorney, only if the skilled nursing facility has an attorney present; 4) An ombudsman. When a citation results from an annual survey and all residents are affected, the following persons may attend: 1) The ombudsman; 2) A representative of the residents or family council at the facility.
Due to the backlog in superior courts around the State, the Attorney General often experiences one or two year delays in securing trial dates for citation enforcement.	Allows citations to be enforced in the court of competent jurisdiction. For amounts below $15,000 this would allow the Attorney General to utilize municipal courts.
Consumer Involvement	
The management information system proposed by DHS should be expanded to be a consumer information system which the public could access through an "800" toll-free line.	Requires development of a consumer information system with the following elements: a) an on-line inquiry system accessible through a statewide toll-free "800" number; b) long-term health care facility profiles; c) information regarding current status of complaints against facilities.

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Establishment of family or resident's councils within each facility should be encouraged. These councils would reduce the threat of intimidation and increase the numbers of consumers who can provide input to the State and long-term care industry.	Requires every licensed long-term health care facility to establish and maintain a patient oriented council.
That the long-term care ombudsman should have a key facilitating role in the coordination of community involvement programs within each service area.	Authorizes ombudsmen to: 1) advise the public of any inspection report for any long-term health care facility; 2) promote visitation programs; 3) establish and assist in development of resident, family, and friends councils; 4) sponsor various other community involvement program. Establishes a civil penalty not to exceed $1,000 for the willful interference with any lawful action of the State Ombudsman Program.
That procedure should be developed to provide ombudsman access to all inspection reports of facilities.	Requires Department of Health Services and the Department of Social Services to provide copies of inspection reports for long-term health care facilities and community care facilities, respectively, upon request.
That systematic effort to obtain publicity for enforcement actions will bring some appreciable amount of coverage that can greatly assist DHS' efforts to obtain correction and deter violations.	Requires DHS to issue a press release whenever a long-term health care facility has its license suspended or revoked, has been placed on receivership, suffers a criminal conviction, is issued an injunction or has federal sanctions imposed against it.
Inspections/Fines/Citations	
The Licensing and Certification Division surveyors do not get an accurate picture of he conditions in facilities because the federally required inspection process is too predictable.	Implement a three-year pilot program designed to lessen predictability of inspection process. Shall include elimination of present practice of entering into a one-year certification agreement and to conduct segmented inspections of a sample of facilities with poor inspection records. Conduct an analysis to determine effectiveness of program in reducing predictability

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	of surveys and the respective cost benefits. (The Federal Government rejected the State's request for waivers.)
The amount of fines have not increased since 1973 while the CPI has increased 117% which has resulted in the current fine structure providing little real incentive to correct or prevent serious violations.	Creates a new "AA" category when the State department determines a violation to be a direct cause of death. Fines for "AA" citation range from $5,000 to $25,000. The State department would be required to prove all the following: a) The violation was a direct proximate cause of death of a patient; b) The death resulted from an occurrence of a nature which the regulation was designed to prevent; c) The patient suffering the death was among the class of persons for whose protection the regulation was adopted. The citation may be reduced if the licensee sustains the burden of proving that the licensee did what might reasonably be expected of a long-term health care facility licensee, acting under similar circumstances, to comply with the regulation. Increases maximum amount for a Class "A" citation to $10,000. Increase range of a Class "B" citation from $100 to $1,000. Establishes criteria the State department shall consider in determining amount of civil penalties. In lieu of contesting a citation a licensee would have to pay the minimum required by law, or 50% of the assessed fine, whichever is greater. If a licensee requests a citation review conference and the citation is sustained for the same class of

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	violation for which it was issued but the penalty assessed is reduced to at least 30% less than the amount originally assessed, the licensee may pay the minimum amount or 50% of the amount determined by the citation review conference, whichever is greater.
Present fines are ineffective for protecting patients' rights violations and deterring retaliation.	Makes patients' rights violations which cause or are likely to cause significant humiliation, anxiety, or fear a "B" violation subject to a fine ranging from $100 to $1,000. Allows trebling of patients' rights violations only when they have a direct effect on the health and safety of residents.
	Raises maximum fine for retaliation from $500 to $10,000. Makes willful retaliation an infraction subject to a fine of no more than $10,000.
	Extends time period for rebuttable presumption from 120 days to 180 days.
	Any effort to terminate the employment of an employee within 120 days of the employee filing a complaint against a facility raises a rebuttable presumption that the action was taken by the licensee in retaliation for the complaint.
Misdemeanor fines for willful and repeated violators should be increased in order to provide a range of potential fines which will actually deter or punish repeat violators and to encourage criminal prosecutions in appropriate cases.	Raises fine to $2,500 per count and establishes criteria a court should consider in determining the punishment to be imposed upon a conviction.
Patient care records which are deliberately falsified should be subject to large and automatic fines.	The civil penalty for willful material falsification or for willful material omission in the health care record of a patient ranges to a maximum of $10,000. A civil penalty ranging from $2,500 to $10,000 will be assessed where the health care record is relied upon by a health care professional to the detriment of a patient by affecting the

	administration of medications, or treatments, the issuance of orders, or the development of plans of care.
	A civil penalty not to exceed $2,500 shall be assessed for all other violations. Establishes a legal presumption that when care is not recorded it is to be presumed that care has not been provided. The presumption may be rebutted by a licensee only upon a showing of a preponderance of evidence.
A method should be found to encourage accurate records otherwise increasing fines for falsified records will likely result in more falsified records.	Encourages facilities to openly identify and document problems by providing facilities immunity from the citation process if all of the following conditions are met: a) Facility has an ongoing quality assurance and patient care audit program which is made available to the State department at the commencement of each investigation and inspection; b) The violation was not willful and resulted in no actual harm to any patient or guest; c) The violation was first discovered by the licensee and was promptly and accurately recorded in the quality assurance log prior to discovery by the State department. (If the violation is initially found as a result of inspection process or investigation of a complaint, a citation will still be issued.) d) Promptly upon discovery, the facility implemented remedial action satisfactory to the State department to correct the violation and prevent a recurrence. If the remedial action is unsatisfactory, the department will allow facility reasonable time to augment the remedial action before a citation is issued.
Some LCD district offices gave lower priority to oral complaints.	Requires DHS to reduce oral complaints to writing and investigate them within the same period as required of written complaints.

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Present law has been interpreted in some instances to preclude citations based on evidence not directly observable by LCD inspectors.	Requires DHS to collect and evaluate all available evidence, including but not limited to observed conditions, statements of witnesses and facility records.
Medi-Cal Discrimination	
Significant numbers of cases were reported to the Commission where residents were evicted when they converted from private-pay status to Medi-Cal. One case involved a 100-year-old woman who had paid $84,000 over a 3-year period only to be evicted after conversion to Medi-Cal. The Commission believes that when a facility admits a resident to its care, it accepts special obligations toward her; that justice demands retention of converting residents by any facility which participates in the Medi-Cal program.	Prohibits long-term health care facilities participating in the Medi-Cal program from evicting a resident who converts from private-pay status to Medi-Cal. The only basis upon which a facility may evict a resident within the first 90 days of admission, is if the facility requests specific information regarding the assets and liabilities of a prospective resident, relies upon the information in deciding to admit the resident, promptly and diligently investigated the assets and discovers that the resident materially misrepresented his/her assets and liabilities.
That facilities do not have a standardized policy of notifying residents in writing, as well as orally, whether or not they participate in the Medi-Cal program. Consequently, a resident may be unaware that because a facility does not participate in the Medi-Cal program, he/she will be evicted when private funds are exhausted.	Requires all long-term health care facilities to reveal to applicants for admission, or their designated representatives, orally and in writing and prior to admission, whether the facility participates in Medi-Cal program, and the circumstances under which the law permits a Medi-Cal recipient to be transferred involuntarily.
That the optional three-day bed hold presently allowed Medi-Cal patients during periods of acute hospitalization is inadequate; that documentation was provided to the Commission that oftentimes a transfer to a hospital provides the facility an opportunity to evict an undesirable resident or one that is converting from private pay to Medi-Cal status.	Requires a 7-day bed hold during an acute period of hospitalization for both private-pay and Medi-Cal patients. If a resident is discharged from an acute hospital within 30 days, the facility must afford the next available bed which is appropriate to the resident's needs and the other needs of the residents.
That Medi-Cal patients are at times discriminated against as to the services provided residents of a facility.	Prohibits a long-term health care facility participating as a provider in the Medi-Cal program from discrimination against a Medi-Cal

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	patient on the basis of the source of payment for the facility's services which are required to be provided to individuals entitled to services under the Medi-Cal program.
Training	
The Commission found that no regular ongoing training program is presented for all LCD staff and that no clear and consistent written regulations and guidelines are available. This has resulted in inconsistency in complaint procedures and in application of standards for issuing citations and fines.	Requires State department to develop, adopt and implement comprehensive continuing orientation and in-service training programs. Requires LCD to maintain program review function responsible for providing consultative support and assistance to LCD field office. ($225,000 allocated through budget process to accomplish this objective.)
	Augmentations to Budget as Signed by Governor Effective July 1, 1984
Resources	
DHS has too few staff dedicated to inspecting facilities and investigating complaints.	20 additional positions provided LCD for inspecting facilities and investigating complaints. The federal department augmented staff by 12 positions totaling 32 additional positions.
Testimony by relatives and facility staff contain numerous examples of poor care on night and weekend shifts. Commission recommends off-hours visits should be encouraged.	Provided $100,000 in overtime funds for off-hour inspections.
No regular ongoing training program is presented for LCD staff.	$225,000 for implementation of training program.
Consumers need more regular access to information.	$300,000 provided to place ads in yellow pages on complaint procedure and toll-free number to call to get profiles of facilities. $50,000 - to establish toll free number. $100,000 - development of pamphlets on how to choose a nursing home and other consumer access information. $300,000 - information on facility profiles to be added on to management information system. $50,000 - travel expenses for members of local advisory committees.

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Since March 1985 when these new laws were enacted, enforcement has increased substantially with many facilities literally being forced out of business due to receiving fines in excess of $100,000 in some cases. Although the "dust is still settling" and some major changes are not yet in place, we believe our elderly are far better protected today.

At this point in time, I would like to discuss the results of our study of conditions in California's community residential care facilities -- particularly those for the elderly.

By definition, a community residential care facility provides nonmedical care and supervision to its residents who include children and the mentally ill in addition to the elderly.

However, care and supervision is not what they receive in far too many facilities. Our nine-month investigation revealed an extensive list of cases of severe abuse and neglect. Specifically, we found that daily throughout this State residents of community care facilities are being sexually abused, beaten, fed spoiled food, forced to live with toilets that don't work, left unattended, and generally subjected to a demeaning existence. In fact, some residents are actually killed in facilities each year. The truly sad fact is that few people, particularly government officials, are aware of the horrible conditions which thousands of community care residents must live in each day.

Our study was not done in isolation of those affected most. In addition to our public hearings and extensive research, we conducted workshops in which we brought together government officials, facility operators, residents and family members, local enforcement officials, and consumer advocates to work with our Commissioners, staff and project consultant towards the objective of developing new approaches and over 30 recommendations to solve the problems.

Among the findings and recommendations were the following:

1. The system for screening individuals applying for a license may be the single weakest link in the community care system. In California, it is easier to get a license to operate a community care facility than it is to get a driver's license. There are virtually no educational or experience requirements to meet. There is also no way to determine if an applicant for a license has had his license revoked in another county. Moreover, although an applicant is screened for a past criminal record, there is no way of knowing whether his employees have a criminal record. We received testimony on various cases in which employees with criminal records raped, beat, and abandoned residents. To correct those problems, we recommended developing minimum qualifications that certain providers will have to meet to receive a license. We also have recommended various steps to tighten the applicant process.

2. The State has also not been adequately prepared to respond to emergencies in facilities. In a Los Angeles facility, mentally disabled residents were abandoned by the operator and left without food or water for over two days. When the situation was discovered on a Sunday evening, there was no way to contact State licensing staff. We believed the State should have a 24-hour/7-day-a-week

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emergency "hot line" for such situations and sponsored the successful enactment of such a system. Additionally, we believe the State should employ a "crisis" team which can actually go into a facility and temporarily operate it when conditions are very bad. We also recommend placing the facility in receivership as another alternative. This recommendation is still under consideration.

3. The existing enforcement system is not strong enough to identify and eliminate the most severe conditions. We cannot continue to tolerate "horror stories" such as:

   - a Southern California facility where bedridden residents were discovered lying in their own excrement;

   - a Napa County facility operator who forced a resident to have sexual relations with him; or

   - numerous facilities throughout the State which threaten residents continuously.

   The State licensing staff needed new enforcement tools to help take action against these facilities and deter future abuses. We recommended several changes including increasing the daily fines for licensing violations by 50 percent and requiring that the fine be tripled in cases of repeat violations; requiring operators to post a performance bond or carry liability insurance; improving coordination with local law enforcement agencies; and increasing the number of State investigators and licensing staff. Many of these items, including higher fines, are reflected in legislation currently awaiting the Governor's signature.

4. Without question, the fastest growing problem in community care is the rapidly increasing number of unlicensed facilities. Many of these operators have had their licenses revoked by the State, but continue to operate in defiance of the law. In one case in Los Angeles County, an unlicensed facility was ordered to stop operating; however, it simply responded by moving to a new location. One resident developed such severe bedsores she required hospitalization. But rather than hospitalize her, the facility simply kept the windows open "because the smell of rotting skin was too bad." The resident eventually died. Because of budget reductions and relative priorities, the State is unable to take action against these facilities. To help remedy this problem, we recommended changes to State law that would provide the necessary legal definitions to enable local law enforcement agencies to take direct action against unlicensed facilities. These changes are reflected in two bills the Governor will sign in the next few weeks.

However, even with improved enforcement tools, the State is faced with an overwhelming task of trying to monitor 22,000 facilities of which about 3,200 serve the elderly. Quite simply, we need more, "sets of eyes" looking at a facility on a more continuous basis. To accomplish this we made several recommendations. First, we believe the State should recruit and train volunteers to monitor residents. This has been very successful in nursing

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homes where volunteer Ombudsmen visit facilities. We also believe residents should be empowered to be monitors by requiring that larger facilities establish resident or family councils. Finally, we recommended that a case management system be established for elderly and mentally disabled persons. These residents have few organized groups overseeing their welfare. Case management would also ensure they receive services which meet their specific needs. Many of these reforms were embodied in California State Senate Bill 185 (Mello) which is currently awaiting the Governor's signature, and will establish a new community care law and system tailored to the needs of the elderly.

I think it's important to note that the community care system in California is literally embryonic in comparison to the nursing home industry. Consequently, the abuses, in our opinion, are far more severe; and the need for reform in California far greater in many respects. At the same time, though, it must be recognized that the reforms needed are more fundamental.

Historically, the community residential care system in California, and most of this country, has been virtually ignored. However, as we continue to see changes in our Medicare and Medicard systems, we will see more and more individuals who should be in nutsing homes forced down into community residential care facilities. As this happens, the problems will become greater in number and more extreme in nature. Government must not put its "head in the sand" until the system explodes.

In conclusion, I would like to briefly identify areas in which I believe the Federal government, and therefore Congress, must focus its attention. As a context to these comments, let me state the following. As depressing and horrific as some of the examples I have shared with you are, all information indicates that California may be literally "light years" ahead of most other states in the quality of care provided in most long-term care facilities. Only through stronger oversight by Congress and the Federal government can society be assured that these forgotten members of our society are protected from the abuses to which they fall victim. This leads me to my specific recommendations:

1. As the Chairman of our Commission, Nathan Shapell, has often stated, "These frail elderly have been left with only one parent -- State government. They must have both a "mother" and a "father" watching over them." The Federal government must become a more active parent, providing more specific guidance on sanctions and providing greater oversight, itself, of the conditions in these facilities.

2. Currently, the states are locked into an inspection process, dictated by Federal guidelines, that is highly predictable and provides only a snapshot of actual conditions. The Federal government must not only allow, but must promote new inspection cycles that are segmented, more frequent, consequently less predictable.

3. Although many will argue that fines are not the best method for promoting compliance, they are effective. The Federal government should promote a requirement that all states use citation and fine systems with fines that hurt as well as cover areas such as patient rights violations and falsification of records.

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4. California has taken some major steps towards dealing with the problem of Medi-Cal evictions. However, it is the Federal government who must act more aggressively in this area.

5. Finally, the best policeman is the consumer. But the consumer is hampered by an inadequate supply of nursing home beds and the absence of easily accessible information on a facility's past enforcement record. The Federal government should take the lead on seeing that every state develops a consumer information system to help consumer to be a smart shopper and bring economic pressure to bear on the bad operator.

This concludes my formal comments today. I want to thank the Chairman and members for offering me an opportunity to speak. I would be happy to answer any questions you may have.

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Mr. PEPPER. Thank you very much, Mr. Mahan.

Our next witness is Mr. Roland Hornbostel, nursing home ombudsman of Cleveland, OH.

We are glad to hear you. I am sorry Ms. Oakar is not here to hear you. She has been anticipating your testimony, but she will read it in the record.

STATEMENT OF ROLAND HORNBOSTEL, NURSING HOME OMBUDSMAN, CLEVELAND, OH

Mr. HORNBOSTEL. Right. I will share that with her later personally.

Thank you, Mr. Chairman, for asking me here today to share with you my perspective as a local long-term care ombudsman.

First of all, I am Rev. Roland Hornbostel. I am the chief complaint investigator for the Cleveland, OH, long-term care ombudsman program. We cover 5 counties in northeast Ohio, containing a 170 nursing homes, and approximately 17,000 nursing home residents.

Despite the problems in identifying the existence of board and care homes that Attorney General Hartigan alluded to in his testimony, we have also identified the existence of over 400 unlicensed board and care facilities in our service area, and we serve the residents of those facilities as well.

Unfortunately, unlike California, Ohio has not seen fit to regulate these facilities in any way. So, there are no regulators and no inspectors that ever go to these facilities and, therefore, it is kind of moot to talk about the rights of residents in these facilities since there are no laws to guarantee them any rights at all to any type of care.

By way of introduction, let me share with you some specific complaint data from the files of our program that I have gleaned over the last year, specifically, in regard to some of the topics we are here today to discuss.

In the past year, myself and our staff in Cleveland have investigated 737 complaints involving nursing home care. Of that total 737 complaints, 112 of those complaints have been alleged violations of residents' rights in long-term care facilities. This is the third largest category of complaints, after simple neglectful care and problems in relation to the Medicaid Benefits Program.

In addition, though the totals are smaller, we have also received 25 complaints involving physical abuse in the last year, and 23 complaints involving verbal abuse in the last year.

Both these figures and also all the testimony that we have had from the first two panels suggest, in fact, you can only draw one conclusion from those statistics and that is that nursing home residents in the United States are denied basic human rights, dignity, and respect that you and I take for granted.

The problem has been, not so much that all nursing homes are abusive or even that all nursing homes are neglectful; but, the problems that we hear over and over again from nursing home residents are the little problems. The things that really make up what people call quality of life in long-term care facilities.

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The right to retire and rise in accord with your own preference, the right to have someone knock at your door, the right to receive your mail unopened, and I use those examples advisedly because one of the things that I think I would like for people to understand is that these rights are either not contained in the Federal bill of rights at all for nursing home patients or are seriously abridged.

The second problem is that residents' rights are simply not considered important by the agencies that we have designated as a Federal Government to regulate long-term care facilities. At present, the health care financing administration can decertify a facility only for violation of a condition or participation.

Also, at present, despite repeated attempts, the Federal bill of rights has never been elevated from being a standard to being a full condition of participation. It is simply one standard under the home policies governing internal governments.

The current Federal bill of rights also lack essential guarantees. First of all, the rights are simply not extensive enough. A number of the rights the residents have mentioned to you today are not guaranteed under the Federal bill of rights at all. The right to private access to a telephone, for example. The right to have your door closed. The right to have someone knock before entering. The right to such things as a clean and safe living environment are not mentioned in the Federal bill of rights.

The second problem is that the Federal rights are written in such vague language that there is an enforcement problem created from the outset. Now, as one who is also an attorney, I sympathesize with members of my profession who make a lot of money telling people what reasonable means and that sort of thing, but to include terms like reasonable creates a real enforcement problem.

I will give you a brief example from the Federal bill of rights. The Federal bill of rights says that you have the right to be free from chemical and physical restraint, except as prescribed by a physician, for a reasonable period of time.

Ohio's own nursing home bill of rights includes language that is quite similar to that, but instead of reasonable, it gives time limited periods during which restraints can be applied, and provides for inspection by a nurse and inspection by a physician before the order is continued.

In other words, we have found from our experience that the more specific the language of the rights, the easier it is to enforce and the greater impact that it has on the nursing home system.

Another, potentially more major problem with the Federal bill of rights, is that even though the current regulations from the health care financing administration suggest that residents do have certain rights, in fact, it is possible for a facility, using one of two mechanisms, to deny all but five of those rights to all of their residents.

The first problem is that the Federal regulations give the attending physician the right to medically contraindicate the exercise of those rights by certain residents.

Some of the rights that can be medically contraindicated are some of the most important first amendment associational rights that we as American citizens possess; such as the right to participate in community activities, the right to receive visitors, and the

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right to privacy. All can be medically contraindicated according to Federal law.

Mr. PEPPER. Excuse me. Do you think there is a need to help get those rights recognized—to have some sort of a statement assuming our standard form of Federal rights, whatever those rights are, up on the walls of all these nursing homes, so that the patients would know what their rights are. They could say, "Congress approved those rights that are on that board up there. I demand that I be permitted to enjoy them."

Would that be helpful, do you think?

Mr. HORNBOSTEL. I think that is one important step to ensure that residents do know what their rights are.

I will just say that what we have done in Ohio to ensure that is every new admittee to the nursing home is given a list of what the bill of rights is and also is provided with a list of telephone numbers of the State surveying agency, of the department on aging, and of any local long-term care ombudsman program, and I think that if you post some of these phone numbers along with the rights, so that they know who to call, when their rights—when they feel that their rights are being violated, that that would also go a long way.

But, certainly, knowledge is power in this regard, and I think that that is one important step.

Mr. PEPPER. And, also, what Mr. Hartigan said, that some good, wholesome, healthy prosecutions would help.

Mr. HORNBOSTEL. Well, that is the point I would like to make next, that there is very definitely an enforcement problem, and I will get to that in one moment.

I did also want to point out that one of the other problems in terms of a nursing home being able to totally abrogate the rights of its patients, though, is the fact that Federal regulations set forth that if a patient exhibits a communication barrier, and that term is never defined, but if a patient exhibits a communication barrier, those rights can devolve to some third party.

This morning, you heard from a resident who very eloquently described what life is like in a nursing home. But, I do not think that there are any of you who were present who could say with certainty that a nursing home could not argue convincingly that Janet Tulloch exhibits a communication barrier.

As long as that term is undefined in Federal law, I think it is easy, right from the outset, for a nursing home to strip the rights from a patient.

I think you were right, Mr. Chairman, when you suggest that enforcement is a big part of the problem. First of all, I do not believe, as has been stated here several times, that criminal prosecutions will totally resolve our problem.

Our experience with criminal prosecutions is that they are good for the most egregious cases, but most of the 112 cases I dealt with last year were not egregious cases, except to the residents who were personally affected by those problems.

I think that there are some other things. While criminal prosecution remains a very important tool, I think other important tools would be to mandate informal grievance procedures, in nursing homes, such as the establishment of residents counsels. Also, to set

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up mechanisms for residents to challenge particular violations of their rights.

Again, an example. Federal law guarantees that residents may be discharged for only one of three reasons: for nonpayment of charges, for their own welfare, or for the welfare of other residents. However, it stops there.

In Ohio, we have extended that protection to give the residents the right to written notice, 30 days in advance of the proposed transfer and to give them a right to challenge that transfer before an impartial hearing held by the Ohio Department of Health.

What this does is stop some of the midnight dumpings on other facilities that several of the people on this panel have mentioned, and I think that that is a fairly important protection.

Finally, and I will just briefly mention this, because it has already been mentioned. Residents should be given a private right of action to sue for violations of their rights. We should not have to depend on the attorney general to bring all the actions on behalf of residents. Residents are perfectly competent of bringing their own actions if they are given the mechanism to do so, and that would have to be, of course, a specific guarantee in Federal law.

The problem of abuse in nursing homes——

Mr. PEPPER. Excuse me just a minute.

You know, it just occurred to me, we are great organizers in this country. What about allowing the occupants of these nursing homes, if they do not do it, maybe they do it already, to form their own little organization, a self-protection organization? Like a local—like a union has some people to look after safety requirements.

Do you not think that would help? Mr. Hartigan indicates he would not approve of that. I was just thinking. I have been in many nursing homes and never without great sadness because I see so many people, some of them cannot speak. Sometimes I go over and speak to them and they cannot respond. If they do, you cannot hear what they say. Some of them are just helpless all around.

It takes great compassion and concern. I can well understand how young caretakers who are inexperienced and nonprofessionals get exacerbated with some of their problems and all. Somebody wants to go to the bathroom too often or something, and they become impatient and the like.

It is a very delicate field and requires very compassionate concern on the part of State and local governments, but I think we are going to take this up at the national department that has supervision over nursing homes. I know the Secretary, Mrs. Heckler, is personally concerned about these matters. We have representatives here today from her Department.

I am going to take this up with her, and see if we cannot get her to set up a real effective organization and program. They could set up a bill of rights and publish them in there and set up procedures for more frequent contact, investigations inspection, and the like, and keep in closer touch with what the States are doing or not doing. If the States were not doing a good job, they could really put the heat on them, let them know that we are not satisfied with the inspections that we are paying for and they are supposed to give,

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and we are going to reduce their money if they do not devote the proper amount of attention to these things.

I interrupted you. Did you finish, Mr. Hornbostel?

Mr. HORNBOSTEL. OK.

Mr. PEPPER. I interrupted you.

Mr. HORNBOSTEL. I would draw your attention to——

Mr. PEPPER. We are going to have to move along because they are pressing me about some other things here. So, please, summarize as best you can.

Mr. HORNBOSTEL. I just wanted to mention very quickly two systemic issues. One is reimbursement. If reimbursement were fair and States are experimenting with different reimbursement systems, such as case mix reimbursement, that control profit and ensure nursing care gets provided to residents, I think that might help.

The second is that very, very shortly, the report that the House of Representatives has commissioned from the Institute of Medicine will be made available to your body, and I believe that that will address some of the more systemic and wide-reaching areas of reform that need to be addressed.

But that report is coming to your body and it would be our hope, as resident advocates, that that report not just sit here but get very careful attention by the Members of the House of Representatives.

[The prepared statement of Mr. Hornbostel follows:]

PREPARED STATEMENT OF REV. ROLAND HORNBOSTEL, NURSING HOME OMBUDSMAN, CLEVELAND, OH

INTRODUCTION

My name is Rev. Roland Hornbostel. I am the Chief Complaint Investigator of the Cleveland Ohio Nursing Home Ombudsman Program. I have held this post for the past 8½ years, since the inception of this program in early 1977. The program is responsible for investigating complaints involving long term care facilities in a five-country area in Northeast Ohio which includes some 170 nursing homes with 17,000 residents. In the past year, our program staff has investigated 738 complaints about long term care facilities in the Cleveland area. Though the majority of complaints concern the care delivered in nursing homes, our organization also investigates complaints about care and services in board and care facilities that house dependent elderly.

I would like, at the outset, to share some statistical data on the types of complaints we receive. While arguably any complaint we handle involves the denial of the basic rights of nursing home residents to adequate care and services in long term care facilties, our complaint data is broken down into more specific categories following the uniform reporting system developed by the Administration on Aging for use by Long Term Care Ombudsman programs. For the purposes of this hearing, I would like to concentrate on three specific categories of complaints. Those categories are: 1) violations of resident rights in long term care facilities as set forth in federal and state law; 2) physical abuse of residents; and 3) verbal abuse of residents. In the past years, we received 112 complaints alleging violations of the nursing home residents' Bill of Rights as set forth in federal regulation or under Ohio statue (§3721.13(A) Ohio Rev. Code.) This constitutes 15.2% of the total complaints received by our program. Of all the complaints received by our program, the category of residents' rights ranks third after nursing care related complaints and Medicaid benefits-related complaints. We received 25 physical abuse complaints last year, constituting 3.4% of the total complaints received. We also received 23 complaints alleging verbal abuse of residents, constituting 3.1% of the total complaints received.

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I. NURSING HOME RESIDENTS ARE DENIED THE BASIC HUMAN RIGHTS, DIGNITY, AND RESPECT THAT YOU AND I TAKE FOR GRANTED

As illustrated from our complaint data, the denial of basic rights, discourteous treatment, and lack of respect are far more frequent occurrences in nursing homes than are physical or verbal abuse. Within the category of residents' rights violations, 30 of those 112 complaints involved the threatened involuntary transfer of residents from a nursing home, 15 involved residents being kept in facilities against their will, and 11 involved the theft of personal items from residents. However, the balance of resident rights complaints involved the denial of rights that you and I take for granted: The right to rise and retire in accordance with personal preference; the right to receive one's mail unopened; the right to receive visitors at a reasonable hour; or the right to have access to a telephone. I mention these rights specifically because under the federal regulations governing Skilled Nursing Facilities, a resident either does not have these rights at all, or his physician, almost always retained by the nursing home, can medically contraindicate the resident's exercise of these rights. A nursing home is a controlled environment, where so often individuality is frowned upon or even denied, where even very basic decisions for residents are made by others.

The sad fact is that often nursing homes act, not out of malice toward their residents, but out of a sense of "doing what is best for our residents." An example of this maternalistic or paternalistic behavior is that members of our staff were assisting the Residents Councils Coalition in conducting a voter registration drive in nursing homes. One nursing home that we contacted told us: "Don't bother coming out here. None of our residents is competent to vote." We could not believe that in a facility with almost 200 residents that not one was competent to vote. Our experience in investigating complaints about long term care facilities suggests to us that the denial or abridgement of residents' rights remains a significant problem. We believe that there are important steps that government can take to protect these rights.

II. RESIDENT RIGHTS ARE CONSIDERED UNIMPORTANT BY THOSE AGENCIES DESIGNATED BY CONGRESS TO PROTECT THOSE RIGHTS

A major problem with enforcing the right of residents in long term care facilities is that the federal government has never considered them very important. Illustrative of this fact is that Federal regulations governing Skilled Nursing Facilities that participate in the Medicare and Medicaid program are broken down into Conditions of Participation, Standards, and Elements. A nursing home can be decertified and its participation in the federal programs terminated only for violation of a Condition of Participation. The regulations governing residents' rights are but one standard nursing homes are required to meet that make up the Condition of Participation on Governing Body and Management. Over five years ago, the Health Care Financing Administration of the Department of Human Services proposed new regulations that would have elevated resident rights to a Condition of Participation. This regulation was withdrawn the day after it was signed. Nursing home residents have waited five long years for further action to protect their rights, yet today resident rights remain just a standard.

III. THE CURRENT FEDERAL REGULATIONS GOVERNING RESIDENT RIGHTS LACK ESSENTIAL GUARANTEES

The current federal regulations governing resident rights contain serious and fundamental flaws. The first is that the list of rights is not extensive enough. Currently the list of rights of residents in Skilled Nursing Facilities enumerates some 14 rights. The Ohio Nursing Home Residents' Bill of Rights, passed in 1979, enumerates some 30 basic rights. The Ohio list adds such rights as the right to a clean and safe living environment, the right to nondiscriminatory provision of care and services, the right to have bed sheets changed, the right to choose physicians, pharmacists, and drug suppliers, the right to consume alcohol and tobacco in controlled circumstances, the right to retire and rise in accordance with personal preference, and the right to reasonable access to a telephone.

A second problem is that the federal rights are couched in such vague terminology that little is guaranteed to the nursing home resident. By way of example, both the Federal regulations and the Ohio Bill of Rights contain precautionary steps that must be taken before a resident can be physically or chemically restrained. The difference in the two approaches to essentially the same problem is that the Ohio law sets specific time limits for which restraints may be imposed, and provides defini-

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tions of what constitute physical and chemical restraints. A second example is that both the Ohio Bill of Rights and federal regulations require that the resident be fully informed of all charges for care (including any item not included in the basic daily rate). However, Ohio law goes on to require that residents be given an itemized monthly bill and 30 days advance notice of any proposed rate increase. In summary, it has been our experience that the more specific the language, the more impact that particular right is likely to have in the daily lives of nursing home residents.

A third major problem with the existing language of the Federal Bill of Rights is that according to the Federal regulation governing the exercise of those rights in Skilled Nursing Facilities, is that all but five of the rights purportedly guaranteed can be medically contraindicated by a physician, or some rights may devolve to a third party if the resident "exhibits a communication barrier." We have serious problems with both of these provisions. First, personal physicians will not follow their patients in most nursing homes. Frequently, the resident is forced to accept a physician provided by the nursing home. Thus, it will be a physician beholden to the nursing home who can make the decision to medically contraindicate the exercise of essential rights by the resident. These essential rights that can be contraindicated include important associational rights such as the right to participate in religious activities, the right to receive visitors, the right to receive one's mail unopened, and the right to share a room with one's spouse. As to the provision that resident rights devolve to a third party where the resident "exhibits a communication barrier" the problem is more serious. Nowhere is "communication barrier" defined. Presumably, this important caveat could be used to deny the exercise of rights by stroke victims, those with CP, or even those who can only communicate in a foreign language.

IV. THE FEDERAL BILL OF RIGHTS IS UNENFORCEABLE

Clearly, the most serious problem with current Federal efforts in regard to resident rights is that they are simply not enforceable. The only penalty for violation of resident rights (or any other violation) is decertification of the nursing home. I think I can safely state to this committee that no nursing home has ever been terminated from the Medicare or Medicaid program for opening a resident's mail, or for restraining a resident without a doctor's order—nor should it be. There is thus *no* penalty for violating a resident's rights. Corrective steps are necessary if these rights are to be enforced. First, I believe that federal regulations should mandate the establishment of informal grievance mechanisms such as Resident Councils so that residents have an effective collective voice in the facility. Second, procedures should be included in Federal regulation to protect specific rights. Again by way of example, both Federal regulation and Ohio law state that a nursing home resident may not be discharged from the facility except for his or her own welfare, for the welfare of other residents, or for non-payment of charges due the nursing home. The key difference between the federal regulation and the Ohio statute is that an Ohio resident must be given a written notice 30 days before the proposed transfer, the notice must specify the reason for the proposed transfer, and the resident is entitled to a hearing before the Ohio Department of Health if he or she objects to the transfer. By way of contrast the Federal regulation provides only that the resident be given "reasonable" advance notice of the discharge—and that notice is provided only "to ensure orderly transfer or discharge" with no right to a hearing. Additionally, the Federal right is of limited effectiveness as it can be medically contraindicated or can devolve to a third party as detailed above. Third, residents should be given the right to sue a facility that has violated their rights. Some states already confer this private right of action on residents, allowing recovery of actual damages, attorney's fees, and, in some cases, punitive damages. If residents had such a right, nursing homes would take residents rights far more seriously than they do at present.

V. PHYSICAL AND VERBAL ABUSE

Over the years, our complaint data has suggested to us that the occurrence of actual abuse of nursing home residents is not as great as the occurrance of neglect, of violation of resident rights, and of Medicaid discrimination. However, abuse complaints are serious problems in that there is little the existing regulatory system can do to prevent abuse. I am happy to say that with one or two possible exceptions, I have never dealt with a nursing home administrator or owner who would knowingly condone abuse in his or her facility. Yet the problem of abuse still persists. Why? First of all, both under the Federal regulatory system and many state regula-

tory systems, including Ohio's, it is unclear who is responsible for the investigation and resolution of abusive situations. The regulatory system, as presently designed, consists basically of structural regulations such as number and type of staff. Paper compliance is favored so that a surveyor called upon to investigate a case of suspected abuse is limited to looking at employee time records to ascertain whether there were appropriate numbers and types of staff on duty, and whether a nursing home had proper written emergency procedures. While the overhaul of the regulatory system is not the subject of this hearing, we await eagerly, as we are sure you also await, the results of the Institute of Medicine Study on Federal nursing home regulation.

It is equally true that the problem of abuse will continue as long as professionals are not required to report instances of abuse to the appropriate authorities. Ohio passed a very fine Adult Abuse, Neglect, and Exploitation Act several years ago which mandated the reporting of suspected abuse of persons over age 60. The duty to report was placed upon most professionals. However, licensed institutions, including nursing homes, were specifically excluded from coverage under the Act. While many states have begun to address this problem, I think that the time has come for a national reporting act.

Verbal abuse of residents by nursing home staff is an even harder problem to handle. Reported cases of verbal abuse are almost impossible to verify as it is hard to get consensus on just what constitutes verbal abuse. Until there is some mandate for training of nurses' aides, for in-services on resident rights, and until nurses' aides are paid an equitable wage for what is an extremely difficult job, such problems will continue.

CONCLUSION

Our experience, as one local Ombudsman program, has led us to suggest that greater emphasis must be place on residents' rights in federal regulations. While the recommendations presented today are by no means an inclusive list, I have suggested that resident rights be broadened to include those rights that so many Americans take for granted. It is equally important that those rights be enforceable. Abuse reporting laws should be enacted to protect residents from physical and verbal abuse. We, as advocates, and you, as our elected officials, as well as concerned providers of long term care, and especially residents themselves must work together to ensure that nursing homes do not strip the dignity and individuality from the nursing home residents of this country.

Mr. PEPPER. Thank you very much, Mr. Hornbostel.

We have another old friend of mine here today, the Honorable Dr. Margaret Jacks, chairwoman of the Florida State Long-Term Care Ombudsman Coordinating Council, in Tallahassee, FL.

For many, many years, Dr. Jacks has been one of the great leaders in this field of care, helping people in every way the State could. The enlightened State policy to which you referred a minute ago to a great degree reflects the enterprising official concern that she has manifested in this area for so long.

So, Dr. Jacks, would you give us a summary of your recommendations, please.

STATEMENT OF MARGARET JACKS, CHAIR, FLORIDA STATE LONG-TERM CARE OMBUDSMAN COORDINATING COUNCIL, TALLAHASSEE, FL

Ms. JACKS. Senator Pepper, I appreciate being here. As we have been sitting here, I have been thinking about the time way back in 1934-35 and later when you worked so diligently nationwide to help our Nation's people——

Mr. PEPPER. I am sorry. I was too young to remember that!

Ms. JACKS. Oh, yes? Remember I was there! So you cannot deny it, or your concern then about helping us to get over the Depression and to try to rebuild some self-esteem and pride back into our Nation and our people—the time when you worked so hard for the

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old age assistance programs and later Medicaid and Medicare. Over the years, we have been very proud in our State to have you as our senior statesman.

Mr. PEPPER. Thank you.

Ms. JACKS. I will try to be a little brief, since we are late.

I have already submitted a written statement, and if I may, I will add some statements in order to include these into what is submitted to the committee.

I will probably sound as though I am bragging about what Florida has done, but we have worked in this program for so very long. I remember so well when we first started trying to license our nursing homes way back in 1952 and 1953, and now we are having the same problems with licensing the adult congregate living facilities--as we call our personal care facilities. We did not start to license them until 1975, and now we are in the licensure process in the personal care facilities in Florida where we were in nursing home licensure 25 years ago.

This is a very serious problem, because we have so many people in Florida who are in between needing nursing home care and still must have care which they cannot receive in their own homes.

As I mentioned earlier, we have the program of Community Care for the Elderly, which has done much to provide services to people in their own homes. I am very proud of Florida for starting this program with general revenue funds. We are now using some Federal funds to expand this program.

The next level of care for people who can no longer remain in their own homes is care in the adult congregate living facility where they can receive board, room, personal care, and supervision. Unfortunately, we are having problems raising the standards in many such homes. One cause of those problems lies in our low payment rate for care. The $463 currently paid is totally inadequate.

We have good structural licensure regulations for such homes, but the staffing requirements for personnel in such homes are not as strong as they should be. They do not require a sufficient number of employees nor are the personnel required to have any particular training.

Unfortunately, in Florida--and this may have happened in other States—through the plan for deinstitutionalization of State mental hospitals, many patients are being released and land in the adult congregate living facilities, where appropriate care is not available.

The people who run these personal care facilities are not able to handle persons needing that level of care. They do not have an understanding of the mental health patient. They do not have enough understanding of older disabled people with mental health problems to even be able to recognize developing problems as they arise. As a result, some of our most serious cases of abuses occur in adult congregate living facilities, where the mentally ill patient is either abused by other patients or the mental health patient abuses the other patients.

We have had many reports of sexual abuse in the ACLF because of this, and although our licensing standards are very good, we do not have enough personnel in the office of licensure to carry out the statutory mandate for licensing the homes providing custodial

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care in an ACLF. This problem is recognized and hopefully will improve, but in the meantime some very bad situations exist.

We are very fortunate this year to have had the legislature provide funds for what we call a mental health overlay. This will provide staff to go into ACLF's to identify patients with mental health problems and will provide special mental health services and provide some help to staff in how to deal with such residents. This is one place where we are making some advances in the care provided.

I would like to share with you very quickly, if I may, some of the additional things that we have been able to do.

Mr. PEPPER. Excuse me, Ms. Jacks. Who pays the keep of the people in those board and care homes?

Ms. JACKS. I am sorry, Senator Pepper. I should have told you. The State makes a supplemental payment to help pay for the cost of care for SSI recipients and for others with that level of income, bringing the payment up to $463 per month.

Unfortunately, there are many people being cared for in ACLF's who need nursing home care, but who cannot qualify for eligibility for Medicaid payments for care, because of excess income, but who also do not have sufficient money to pay for their care as a private pay patient.

ACLF's by law are not supposed to give any nursing care, but, unfortunately, because the families do not know what to do with such ill patients or the doctor says, "Well, try and put them in an ACLF," many of these adult congregate living facilities just go ahead and accept these ill people, an act which jeopardizes their license, for one thing, and results in the people not getting the kind of care they should get.

As a result of such inappropriate placement, such patients are neglected; they do not get the medical care they need. It is a very bad situation. It is one of the worst situations in Florida that we have to deal with at this pcint in care for the long-term care patient.

Mr. PEPPER. Now, are those board and care homes provided by local entrepreneurs?

Ms. JACKS. Yes. However, I should not say that they all are. We have 40,000 people in ACLF's in Florida, and some of those are in the life care facilities where they are provided a continuum of care, and part of that continuum of care includes care in an ACLF when such is needed. Many of these facilities are run by churches and other nonprofit groups.

I do not worry about those because their care is usually very good. The care in the ACLF's that are under proprietary ownership, private ownership, are the ones where the care is many times unacceptable.

Mr. PEPPER. Ms. Jacks, I have heard in different places that the States, I do not know whether Florida is doing it or not, I hope not, that the States are pushing patients out of their mental institutions.

Ms. JACKS. That is what the deinstitutionalization is all about.

Mr. PEPPER. Pushing them out into this kind of an institution that you are telling about?

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Ms. JACKS. I understand that this is happening nationally—at least in many States and I know it is true in Florida. The mental health program tries to make some plan for their care in the community, but too frequently there is little or no followup and many of the people land in a community without appropriate services being available to them.

Mr. PEPPER. See, they push them under SSI.

Ms. JACKS. Yes. Many of them are getting SSI.

Mr. PEPPER. But when they are in the mental institutions, they are under State expense.

Ms. JACKS. Yes, but all they have when they get out is frequently their SSI benefit payment.

Mr. PEPPER. When the State gets rid of them, they get the benefit of SSI.

Ms. JACKS. There is no Federal money that goes to them, except what the people get from their own resources, their SSI, or their Social Security grant. The State does, however, give a supplemental payment, if they are put into an ACLF.

Mr. PEPPER. But it is the way of the States sort of shedding the obligation.

Ms. JACKS. That is right, with respect to adequately meeting their needs.

Mr. PEPPER. Do you have some of it in Illinois, too, Mr. Hartigan?

Mr. HARTIGAN. Yes, sir. We do, and one of the aspects of it is that the people are scared to death. We have had people come in from nursing homes and talk about what the doctor is talking about, that the people will roam, they cannot control themselves, they have no idea that they are hurting other patients; they simply are mentally ill, and there is no separation, there is no security.

The State closed in Illinois, Dixon, Bow, and Adler, a whole range of institutions that never should have been closed, allegedly to deinstitutionalize into community based care. Community based care did not exist so they dumped them in the nursing homes, and these were some of the things that I was explaining earlier, and then the security factor that the doctor is talking about inside those homes.

Those people are literally scared to death.

Ms. JACKS. You see——

Mr. PEPPER. I understand that. Yes, Ms. Jacks?

Ms. JACKS. In addition to that, for those people in ACLF's who may have mental health problems or who are wanderers, as we say, but have not been adjudged incompetent. The same thing happens because of insufficient staff to provide proper supervision to people who evidence continued mental health problems.

We have had two situations recently in Florida which bring up the conflict that can occur between the denial of the right of an individual to free access and exit from a facility and the protective services for that same resident who may need to be protected against wandering away and getting injured because he/she was not restrained.

In one incident, the wanderer went outside the yard onto a highway and was killed.

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Fire and safety requirements do not permit locked doors. Recently, an ACLF with some such patients did keep an outside door locked. A fire occurred and two people burned to death.

How can these two situations be avoided? My only suggestion is to provide more staff and better trained staff so supervising can be provided without restraints being used.

Mr. PEPPER. It just occurred to me, while you were speaking, we have a United States—what is the aging office here? Office on Aging. Does that office supposedly have jurisdiction over these areas we have been talking about?

Ms. JACKS. No. This is a State problem.

Mr. PEPPER. Well, the more you all talk, the more I am convinced that it is a tragic—I mean, the tragic abrogation of our responsibility. Now, is there any other agency of the Federal Government whose job it is to keep—I think about the States pushing people out. Somebody ought to be in touch with us and say wait a minute, you—if you are pushing these people out in order to get Federal funds, why you have got to meet certain criteria.

Ms. JACKS. They are not doing it just to get people back in the community as far as Florida is concerned, Senator Pepper. I have to tell you this is being done by the legislature because it appears to be the most cost-effective way to provide for many people who need continuing mental health services but are not acutely mentally ill and do not need to be in a mental hospital.

Mr. PEPPER. The State wants to save money.

Ms. JACKS. That is right.

Mr. PEPPER. I do not say there is an evil purpose. They are saving money.

Ms. JACKS. They are trying to save money in what they believe to be the most cost-effective way of caring for such patients.

Mr. PEPPER. Yes.

Ms. JACKS. I would challenge deinstitutionalization, and I have challenged it in the legislature in Florida—if people are being taken out of an institution when there are not resources in that community to take care of them. It is bad when this happens.

Mr. PEPPER. OK.

Ms. JACKS. It is really a serious situation.

Mr. PEPPER. Have you any affirmative suggestions, Ms. Jacks, as to what we should do about this matter?

Ms. JACKS. Well, I have some suggestions but in light of all we have done in Florida I am not sure we could have, to date, made much more progress. We have, since 1982, improved our standards for licensing of nursing homes and ACLF's so that we have an almost model law. The statutes include many of the things mentioned here today as being desirable, such as provision for a receivership, referral to the State's attorney in cases of verified abuse. In one case last year, an administrator of an ACLF received a 5-year sentence for neglect of residents in his home and for accepting residents his facility was not equipped to care for.

We have the tools in Florida—we have strict rules and regulations for the office of licensure to follow. We do need more staff.

We have the long-term ombudsman committee set up in Florida by statute. We have a State ombudsman council, and one council in every district of the State department of health and rehabilitative

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services who do respond to any complaints. The councils work with OLC—office of licensure—to see that they follow up on such reports.

We also work with the adult abuse office of HRS in a nursing home or ACLF complaint. So, we have done a lot of things. I am very proud of it, but with all we have done, I could not say to you that there are not people being abused in the State of Florida. If I had time, I would verbally give you some statistics which I have included in my written statement.

Mr. PEPPER. One time I mentioned to our distinguished Governor, the appointment of elderly people as inspectors, and the Governor first agreed to that on the recommendation that his great wife, who is so keenly interested in the subject of the elderly, then he said no, wait a minute, how about if I consult my agents before I agree to that, and so far as I am aware, nothing has been done about it lately.

But, if you have an opportunity to check up on the inspection system, and see whether or not there is continued visiting on the list of inspections——

Ms. JACKS. The inspections——

Mr. PEPPER [continuing]. That will—excuse me. When they go through a nursing home, they will look for something other than the building being physically clean, which is, of course, essential. But, they ought to know enough to talk to some of those senior citizens.

Ms. JACKS. Our law has a bill of rights in it, and lisensure staff are enforcing it. They are checking every nursing home when they go in. They check on the bill of rights.

I would like to make two suggestions——

Mr. PEPPER. You mean the ordinary bill of rights? The constitutional bill of rights?

Ms. JACKS. No. We have a bill of rights similar to the one that you are trying to get through.

Mr. PEPPER. Oh, good. You do. That is fine.

Ms. JACKS. Yes, we already have that.

Mr. PEPPER. Send me a copy of it, if you will.

Ms. JACKS. I will send you a copy of the statutes and the rules and regulations.

Mr. PEPPER. Thank you.

Ms. JACKS. The other thing that I think is important for us to look at, though—you mentioned this in your opening statement, Senator Pepper, I do not think a lot of people know what we are talking about when we say the bill of rights.

They think about people going into nursing homes and they know that they must be fed and they must be kept clean and other aspects of physical care, but they do not think about the things in the home that affect the person's feeling about himself, you might call it the psychosocial needs of the older person, his need for privacy, the things you mentioned, the need for having some freedom and some part in the decisionmaking as to his own care—all of those things that affect the quality of life of people in long-term care facilities.

Mr. PEPPER. Ms, Jacks, let me say that to all of you, this is a wonderful panel. When you get home or afterwards, if you think of

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anything that would be helpful to us in this general area, please write me a note about it. I would be very grateful and we will make the best possible use of it.

Ms. JACKS. We really need to have a strong educational program. The ombudsmen in our State, incidentially, work with the legislature and with the Department of Health and Rehabilitative Services, so that we prepare a pamphlet that goes to all nursing homes, goes to the applicants and goes to the relatives of applicants, to define the rights and what action they can take in case those rights are denied, and that is also a part of the requirement of licensure.

They have to check to be sure these pamphlets are being used. So, we have also listed the resources available to the patient to be used in assuring that rights are enforced.

Mr. PEPPER. That is very good.

Ms. JACKS. We have and I cannot help but say this, Senator Pepper, I think we really have to look at what real value a statutory basis for standards carries with it.

I have been in this field a long time, and I have found that, historically, unless you have a sound legal statutory basis for your rules and regulations, so you can go back to those as a reference, nothing really happens.

Mr. PEPPER. That is right.

Ms. JACKS. Unless we have that framework, we are not going to be able to protect our older peole.

Mr. PEPPER. Thank you very much, Ms. Jacks. I am very grateful to you for that.

Ms. JACKS. Thank you.

Mr. PEPPER. For anything else that you will send me.

Ms. JACKS. Well, I will send something in an additional statement, if I may.

[The prepared statement of Ms. Jacks follows:]

PREPARED STATEMENT OF MARGARET H. JACKS, ACSW, CHAIRMAN OF THE FLORIDA STATE LONG-TERM CARE OMBUDSMAN COUNCIL

I am Margaret H. Jacks, a former director of the Division on Aging of the Florida Department of Health and Rehabilitative Services, speaking today as chairman of the State Long-Term Care Ombudsman Council of Florida.

Senator Pepper and committee members, I appreciate the opportunity to appear before this distinguished committee. We in Florida have the deepest appreciation for what your committee is doing in bringing before our nation the problems which face us in our attempts to plan for acceptable care for our older citizens who must be cared for in long-term care facilities.

Senator Pepper, your concerns for all people in need and your attempts to protect their basic and special rights go a long way back. I remember so well the years when we worked together during the desperate years of the "Great Depression" and afterward to rebuild the nation's feeling of self-respect and self-worth so badly damaged by those tragic years. We in Florida watched with pride your efforts to pass and implement the Social Security programs including the title which provided the Old Age Assistance Program and later the other programs of Medicare and Medicaid. We deeply appreciate your continued, consistent efforts over the years to improve the quality of life of our older citizens, particularly the frail vulnerable patients in all long-term care facilities.

In recent years, we in Florida have tried very hard to write into our statutes specific standards for acceptable care, hoping through licensure requirements to clarify the level of care that will best meet basic and special needs of persons being cared for in such facilities. We have also, by statute, established the state program of long-term care ombudsman councils as an added service directed at responding to the

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complaint of long-term care patients or others acting on their behalf and, when possible, resolving such complaints.

The implementation of those improved statutory standards has added strength to our licensure programs. Even with all we have done, I cannot with any conviction state that the rights of all of the patients (or residents) of long-term care facilities are being protected. To the contrary, I believe I am safe in saying that in many nursing homes and an even larger percentage of adult congregate living facilities which provide board, room, personal care, and supervision, the rights of the residents are not recognized nor protected. I am not even sure that people in the community nor staff of the facilities really understand the value of those rights in maintaining an acceptable quality of life for the individual.

Many facilities do provide excellent care; unfortunately, many do not. I would suggest that, in addition to a strong statutory base for licensure which mandates good care, it is the responsibility of the nursing home industry to also discipline itself in order to improve patient care. Any outside inspection team can go only so far in its effort to insure acceptable care for the patients. The facility in the last analysis must guarantee an acceptable quality of life for the patients in their care.

There exists in the mind of many individuals that, with institutionalization, a person must always give up many rights and conform to a routine existence which may meet the test of ease of administration for the facility, but provides little consideration of patients' individual personal desires. In fact, that concept is the root of the dread of being put into an institution. Part of the problem seems to lie in the administrative policies and procedures of the long-term care facility which include rigidly enforcing its rules.

These administrative regulations frequently control the hours for meals, diet, time for bathing, sleeping, recreation, room decoration, available staff time for providing personal care, etc., all of which facilitate administrative goals of the facility, but give little consideration to patients' care. For example, I cite one nursing home where patients were awakened between 5:00 a.m. and 7:00 a.m., and rushed into a shower after which they were put back to bed only to be left without being clothed or fed for several hours. This type of situation need not occur—for the goal of good institutional care must be focused on the meeting of the needs of the patient. This patient care focus, however, does not occur unless it is mandated by required, clearly-defined standards of care which are monitored and enforced.

In fact, I cannot overemphasize the value and added strength of having the patients' rights spelled out in the state statutes and being given the same status as other statutory requirements with the same potential sanctions for non-compliance as have other requirements for licensure. Unless "rights" are spelled out clearly and enforced, they may be considered by most people—patients, relatives and the general public—as somewhat nebulous, unclear philosophical concepts, such as "good" patient care. Without this needed emphasis and such clearly identified requirements, the institution may well try to justify their failure to provide for meeting such rights by pointing out that institutional living cannot permit such individualization of the patient—that living in an institution "requires" a patient to give up some of those rights which he or she might automatically expect in his own home but not in an institution. This attitude on the part of the facility staff is just a "cop out" by the institution which places the value of routine of ease of administration above that of the well-being of the patient.

Because we find that the denial of patients' rights is frequently ignored in the licensure process, we strongly recommend that the requirement for the protection and maintenance of patient rights be raised to a condition of participation. These rights which must be recognized and enforced include among others:

(1) The right to freedom of speech without fear of reprisal.

(2) The right to privacy as a part of the maintenance of personal dignity.

(3) The right to handle one's own personal and financial affairs as long as capacity to do so exists and competence has not been removed by established judicial procedures.

(4) The right to adequate and appropriate physicial and health care. Unfortunately, the denial of that right is often a joint failure shared by the patients' physician as well as the facility providing care. The facility cannot make a member of the medical profession make needed calls to the facility—nor require that the physician actually see the patient and review earlier plans for care to update treatment plans as the patient's condition may require.

(5) The right to privacy in communications and freedom of association without under restrictions as to the time and in a place which assures privacy of discussion with family and friends; "no place to talk" is perhaps one of the most frequently

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denied rights because of lack of specific space, particularly in a shared room arrangement.

(6) The right to the retention and use of personal belongings, a denial which often occurs. The lack of such rights is demeaning to the patient and may, in fact, be serious to the overall well-being of the patient if it involves loss of dentures, hearing aids, family pictures, possessions that have great meaning for the patient and cannot be replaced and may result in deep depression.

(7) The right to choices and opportunities to participate in decisionmaking. This perhaps is the right which best preserves the individual's feeling of self-worth and security of being at least partially in control of one's future and lends itself to fulfillment in many simple ways by the facility whose employees really care. The way a patient is to be addressed—as Mrs., or Mr., unless the patient wishes it otherwise—a choice as to apparel that is to be worn, freedom as to when to be bathed, when to turn a light off, some choices in food, etc., all contribute to a feeling of being in control. Recognition of religious rights should be basic to the plan for care of any patient, particularly where it affects dietary standards and observance of holy days, etc.

To be treated with respect and to have one's dignity preserved is the right of all persons who must depend on others for care—this is really the basic foundation of all rights.

In the Florida State Long-Term Care Ombudsman Council's annual report to the Governor and the State Legislature, statistical data is included as to the frequency of complaints which reflect a denial of patients' or residents' rights as a way of developing an awareness of residents' rights. Last year (1984-85), throughout the State of Florida, the long-term care ombudsman councils received 537 complaints involving violation of the rights of nursing home and adult congregate living facility residents. These compliants involving the rights of residents comprised 22 percent of all complaints received and investigated by the ombudsman councils last year.

Among the typs of residents' rights violations investigated by the ombudsmen were the following:

Transfers or discharges in violation of residents' rights;
Denial of the right to manage personal financial affairs;
Denial of access to adequate and appropriate health care;
Denial of privacy and freedom of association and communication;
Denial of the use or retention of personal belongings;
Not treated with dignity or respect;
Denial of the right to participate in religious and social programs.

The previously-referenced figures pertain to violations of residents' rights specified in Florida law. Another 578 complaints included such problems as residents not kept clean, improper use of restraints, facilities infested with roaches and other insects, and inadequate food service.

The types of situations behind the statistics are varied and in some instances extremely alarming:

The right to choice was clearly denied in a complaint originating in a nursing home where two long-term, congenial roommates were abruptly separated when one became Medicaid-eligible and was transferred to a "Medicaid bed" in another section of the facility without either patient being notified of the change being made. It was the patient who remained in the room as a private-pay patient who was extremely upset over the change. Both patients had provided many services for the other. The quality of their lives—their feelings of adequacy and of selfworth—were badly damaged by the change.

The right to personal privacy was consistently denied to the residents of a personal care facility run by a man and his spouse. The wife, who was supposed to provide personal care to the female residents—help bathing, toileting, etc.—accepted outside employment. As a result of her absence from the home, all personal care had to be provided by the man, including giving showers, etc. The situation became extremely acute when inappropriate sexual conduct on the part of the administrator was strongly suspected.

A troubling case of the violation of residents' rights occurred during the past year in a south Florida nursing home. This case was fully substantiated and included allegations of understaffing, residents not assisted in eating, and residents awakened too early. Because there were too few nurses and nurses aides, staff persons were unable to provide assistance to blind and otherwise disabled elderly residents during mealtime. As as result, many of these reisdents went without meals. These residents included insulin-dependent diabetics, one of whom was noticed by an ombudsman council member who immediately visited the kitchen and made arrangements to assure that the resident be given assistance in eating his meals.

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In that same facility, as a direct result of insufficient staff, elderly residents were awakened routinely at 4:30 a.m. in the morning to be bathed and dressed so that the morning shift would not have to provide that care before breakfast. No consideration was given to residents' objections to being awakened in the "middle-of-the-night," and many residents were observed slumped in their chairs asleep, where they remained, many of them, most of the day.

Another example of resident's rights violations occurred in a nursing home where attempts to ease the duties of its dietary department resulted in the facility ceasing to serve breakfast in the dining room. All residents were being fed the morning meal in their rooms, in bed.

This incensed residents and family members alike since this decision on the part of the administrator was devoid of any sensitivity to the need to get residents out of their rooms and participating in social activities, one of the most important of which is mealtime socializing. In this case, ombudsman council members expressed their concerns and disapproval to the administrator who, fortunately, immediately reversed his decision. There are frequent complaints of the failure to preserve a patient's rights to privacy when doors are not shut or curtains not drawn when treatments are being rendered.

Many older persons do become "wanderers" because of conditions that result in disorientation and confusion. Some of these conditions are temporary. However, unless the resident's competency has been removed, the facility must recognize that the right of the individual to self-determination and to freedom of access and exit should be protected, particularly as a concern in a personal care facility where use of restraints, use of locked doors, locked outside exits and gates is unlawful primarily because it may become a fire hazard for ambulatory patients. In such a case, that same right to freedom of access and exit may become a hazard which requires protective supervision of the individual. When this happens, the protection of the rights of the frail older persons and the provision of protective services may be in conflict. Such a situation occurred recently in Florida when two residents in a personal care facility died in a fire because exits were locked. In another situation, a resident who "wandered," was not restrained in any way, walked out in to the highway on which a personal care facility was located and was killed. At what point does the administrator of a facility make a decision against observing the patient's right to self-decision if there is no determination of incompetence and the patient's actions result in positive danger to him or her.

A verified complaint in a personal care facility told of three residents who, because they had a tendency to wander, were padlocked in their rooms from 5:00 p.m. until morning. One check was made at 10:00 p.m., but otherwise they were left unattended. This situation came to light when an attendant at the home make a point of sharing her concern with a visitor at the home. This sharing took place when the owner was absent since all staff had strict orders not to talk with anyone about patients' care.

It is suggested in trying to resolve this dilemma of "rights versus protective services" that: 1) the problem be recognized with no lessening of concern over undue use of restraints in personal care, and 2) the requirement for more adequate staffing patterns be fulfilled to provide supervision by staff as required by the facility's patient case mix.

With the recognition of patients'/residents' rights, there has also been a growing recognition in Florida of the need for a better understanding of what is meant by denial of rights. Patients and/or relatives anticipate that the cost of care of the patient (resident) will meet basic needs of food, shelter, supervision and/or nursing services. However, there is not a similar understanding of the need for or provision for meeting the psycho-social needs of the individual which include the meeting of patients' rights.

When complaints are received, they usually relate to the lack of physical care, neglect or abuse. There are infrequent complaints that report situations which affect the quality of life such as the feeling of self-worth, loss of dignity, the maintenance of a maximum degree of independence, the right of self-determination or the security that comes with the feeling of being in control of one's destiny. Nor do the complaints refer to the lack of choices or a failure to be involved in decision making about one's current and future well-being.

To facilitate the recognition of such psycho-social needs of residents of long-term care facilities and the result which the denial of patients' rights has on the meeting of those needs, the Florida State Long-Term Care Ombudsman Council has worked with the Florida Legislature to include in State statutes a statement of patients's rights in personal care facilities and in nursing homes. To assist in implementing the statutory requirements, the State Long-Term Care Ombudsman Council has pre-

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pared written pamphlets which, by state rules and regulations, must be made available to all applicants for care and/or to their relatives. In other words, this is not just a service to inform residents of their rights, but to require that those rights not be denied. Also, as mentioned earlier, the wide distribution throughout the State of the annual report of the long-term care ombudsman councils is an educational effort to develop an understanding of the rights of the patients and the extent to which the denial of those rights lessens the quality of life for the residents. We urge that similar educational attempts be initiated elsewhere if this is not already being done.

It is only when there is a true understanding of the value of the basic rights of persons living in long-term care facilities, that the well-being of those residents can be fully realized.

Mr. PEPPER. Now, our next witness is Mrs. Patricia Nemore, attorney, National Senior Citizens Law Center, in Washington.

Will you give us a summary, Mrs. Nemore, of your recommendations?

STATEMENT OF PATRICIA NEMORE, ATTORNEY, NATIONAL SENIOR CITIZENS LAW CENTER, WASHINGTON, DC

Ms. NEMORE. Yes. Thank you very much.

Mr. Chairman, I would like to just describe the law center, the National Senior Citizens Law Center is a publicly and privately funded law center that works with legal services attorneys, private attorneys, long-term care ombudsmen, and attorneys generals and others seeking to enforce, in my case, the rights of nursing home residents and for other people at the center, other rights of the older people.

My testimony today will focus on areas of the private enforcement system. We have heard from other witnesses about public enforcement and some of the difficulties with that and some things that States have done to improve the public enforcement system.

I would like to discuss some of the reasons why so little is done in the area of private enforcement to protect residents' rights, what some of the barriers are and where there have been some successful efforts to enforce residents' rights from a private point of view.

We have heard today all about the various kinds of violations. I was happy to hear some of the witnesses talk about the Medicaid discrimination problems. Despite all of the abuses that we hear about and how widespread they are, residents and their families and their advocates very rarely use the legal system to vindicate their rights.

One major reason for that is that it takes a very long time to take a case through court. One of the most important nursing home cases that we know about is the case of *Smith* v. *Heckler*, which has now come down after 10 years in the courts, issuing an order to the Secretary of HHS to develop and promulgate regulations through which she can ensure that residents are getting quality care.

We are very pleased with the outcome of this case so far, but it has taken 10 years to get that far. We hope that in the course of developing those regulations, that maybe some of the other problems that we have heard about today can be addressed.

Some of the witnesses have testified about families abandoning their elderly relatives to nursing homes, but we know that many families do not abandon their relatives, but they do often lack in-

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formation through which they can be informed about the rights of nursing home residents.

Many State governments, for example, have taken action to declare private pay duration of stay contracts illegal, and, yet, many residents will enter into those contracts because they do not know of those actions or they are misinformed by the nursing home. We are told that if they do press the issue, the nursing home will back down and agree to dissolve the contract, but most residents do not know to do that.

People seeking admission to a nursing home may perceive that they have few options and sometimes they are forced to sign contracts that contain many questionably legal clauses because they really do not see that there are other nursing homes available to them or other community based long-term care options.

So they sign contracts. Even if they are aware that there may be violations of their rights, they do not see that they have options.

Often, we find that residents or their families may be embarrassed by the issues that might give rise to some actions. We have heard a number of instances where States have taken action against facilities for double billing, billing both the Medicaid resident and the Medicaid Program for incontinent pads and for diapers, but the residents may be too embarrassed by that particular kind of a problem to come forward with it.

But, mostly, what we have heard people talk about today is fear of retaliation. Residents are isolated from the community; they may not have many relatives and they are almost totally dependent on the facility. We have been told by attorneys who do litigate for nursing home residents that they believe that residents may receive better care when there is a case in litigation because both the attorneys for both sides and the judge are focusing attention on the facility. But, it is difficult to persuade people of that.

There are other barriers as well. Sometimes, attorneys, ombudsmen, other advocates for the elderly, have difficulty gaining access to facilities. There is no Federal access legislation and many States do not have access legislation.

The lawsuits that have challenged access problems have had varying degrees of success. Basically, the cases are based on constitutional claims, and it is very difficult to raise constitutional claims against nursing homes because they are nominally private enterprises. So, the absence of clearly defined legislation access has been a problem.

Also, the unavailability of attorneys knowledgeable about nursing home residents rights makes a lot of legal solutions unlikely. There are some attorneys who know something about the complex body of law that governs nursing homes, but most of those attorneys represent facilities.

In recent years, personal injury lawyers have begun to be interested in representing nursing home residents, but many of their cases are brought as wrongful death actions and that is really too late to help the resident. We hope that those kinds of actions help people in the future.

Moreover, in cases like that, the jury awards or settlements for those residents, have been based on noneconomic damage theories because nursing home residents often do not have economic dam-

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ages, such as loss of wages or out of pocket medical costs. So, the damages are pain and suffering, mental anguish, and punitive damages.

As I am sure we are all aware, in recent years, both at the State and Federal level, there have been legislative efforts that purport to deal with difficulty of health care providers in getting malpractice insurance, but those efforts would oftentimes cutoff peoples rights to go to court to pursue noneconomic damages.

Some of the attorneys who are most familiar with the laws relating to nursing home residents are legal services attorneys. However, many legal services field programs attorneys are swamped by the problems of clients who come to their offices. They have little time to ride circuit to area nursing homes, only to be denied access or to meet with reluctance on the part of the residents to pursue a claim.

There is also just a very small body of case law in the nursing home area concerning protecting residents rights. Many legal theories have been raised in litigation but few of them have been ruled on by courts, and on such threshold issues as whether the Medicaid law provides for a private right of action implied in the statute, courts have been divided.

So, there needs to be some clear direction on that, and in the area of public enforcement, although other people have focused a lot more attention on that, one of the problems is that the residents rights that we do have in Federal regulations are a standard in the regulations; they are not a condition of participation.

Mr. PEPPER. Are there any standards, either in the provisions for Federal law or regulation, as to how nursing homes, for example, must be operated and the rights of the people there observed?

Ms. NEMORE. They are largely in regulations and there are—the regulations are quite considerable, but difficult to enforce, as we have heard. There is language in the Federal law that is very useful, I think, for nursing home residents, but we have had difficulty in figuring out——

Mr. PEPPER. How does the Government proceed to the enforcement of those regulations?

Ms. NEMORE. Excuse me?

Mr. PEPPER. How does the Government enforce those requirements?

Ms. NEMORE. How does the Federal Government?

Mr. PEPPER. Yes.

Ms. NEMORE. Well, the Federal Government has pursued the position for 10 years at least, if not longer, that it is largely the States' responsibility to enforce the Federal regulations because of——

Mr. PEPPER. How do they do it? Do they have inspectors that go into these homes? How do they do it?

Ms. NEMORE. Yes. Through the States having inspectors.

Mr. PEPPER. I am not talking about the States; I am talking about the Federal Government.

Ms. NEMORE. The Federal Government has some inspectors. Generally, they do validation surveys of the State systems to ensure that because they—in the Medicare program, they contract with the States and——

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Mr. PEPPER. Is there any reason why the States have inspectors for some institutions and not for others? I mean, the Federal Government?

Ms. NEMORE. Why——

Mr. PEPPER. Do you know of any reason for that? I understand that there are—what is it—3,000 or something like that, that the Federal Government has inspection authority over. A great mass of them, however, the Federal Government does not provide inspection for.

Ms. NEMORE. Well, there is some provisions in the law that——

Mr. PEPPER. My staff director tells me that the Federal Government inspects only 3 percent of the nursing homes.

Ms. NEMORE. Those are mostly either validation surveys or what are called look-behind surveys, when the Federal Government feels that the State has not done an adequate job——

Mr. PEPPER. Why do they limit their inspectors to 3 percent? Do you know?

Ms. NEMORE. The—I believe it is in the Medicaid statute that there is a provision for paying the States to do the Medicaid inspections and with the Medicare Program, there is a provision for contracting with the States and that is how the statute is set up.

Mr. PEPPER. Thank you very much.

Could you give us a summary of the remainder of your material?

Ms. NEMORE. Yes. I would like to just make some recommendations here, several of which we have heard from a number of the witnesses.

There needs to be legislation or at the very least the elevation of the residents' rights provisions currently in the Federal regulations to a condition of participation. Federal legislation would probably be preferable.

The Medicaid law should be amended to expressly include a private right of action for recipients of Medicaid against Medicaid providers.

Legislation should be enacted to ensure access by attorneys and other advocates to institutions where vulnerable people reside.

We need to encourage funding in the legal services programs for specialists to represent nursing home residents, and we need to liberalize regulations in legal services concerning group representation. This is one way of overcoming residents fear of retaliation, is to be able to represent groups instead of individuals.

We need to discourage the malpractice related activities that would deny access to the courts to pursue claims for noneconomic damages.

We need some clear direction from the Health Care Financing Administration concerning its interpretations of Federal law.

We need to encourage the development and dissemination of programs to educate nursing home residents and their families and the communities and the facilities about residents rights.

We need to encourage greater national support for the long-term care ombudsman program, and we need to encourage more involvement by States, attorneys general who have been very successful in some States, in helping to pursue residents rights.

And, we should clarify by legislation, if necessary, the mandate of the Medicaid fraud agencies so that they will pursue problems of

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resident abuse, of resident fund abuse, and not merely concentrate on financial fraud against the Medicaid Programs.

And, I would like to also support other recommendations that have been made by other witnesses today.

[The prepared statement of Ms. Nemore follows:]

PREPARED STATEMENT OF PATRICIA NEMORE, NATIONAL SENIOR CITIZENS LAW CENTER

I am Patricia Nemore, a staff attorney at the National Senior Citizens Law Center. The Law Center is funded by the Legal Services Corporation, the Administration on Aging and private foundations to provide technical assistance and other support services to legal services attorneys and other advocates for older people. My own area of specialization at the Law Center is nursing homes. I am in nearly daily contact with legal services attorneys, private attorneys, long-term care ombudsmen and others seeking to enforce the rights of nursing home residents. I am happy to respond to the Chairman's request for our testimony on this subject, and thank you for the opportunity.

In my testimony today, I will first describe the violations of residents rights that we hear about most often. Then I will talk about the many barriers, legal and otherwise, to challenging those violations. Finally, I will describe instances where residents and their advocates have overcome the barriers and successfully vindicated their rights.

VIOLATIONS OF RESIDENTS' RIGHTS

Violations of residents' rights range from incidents of life-threatening abuse or neglect, to incidents of rudeness. Problems arise before individuals even become residents. They may be denied admission to a facility because they are Medicaid recipients or because they or their families cannot pay the private rate for the period the facility requires, often between one and three years.

To get into a facility, prospective residents may have to sign an admissions agreement containing many terms of questionable legality. Such terms include sweeping waivers of liability for any harm or loss suffered by the resident while in the facility. The questionably legal contracts may also include limitations on the applicant/resident's right to use Medicaid benefits, restrictions relating to medical care or nursing services, and improper financial terms or requirements. They may also require the applicant/resident to have a co-signor.

Once in the facility, a resident may not receive needed treatment, such as care for decubitus ulcers, or rehabilitative services that would help her maintain or regain some level of independent functioning.

A resident may be transferred to a hospital for an alleged emergency that does not, in fact, exist, then denied readmission to the facility. Or, when the resident's private funds are exhausted, she and her family may be told that the facility has no available Medicaid beds. Residents may be subject to illegal and unethical drug experimentation without their consent.

Property may be stolen or lost—money and other personal possessions that represent the remaining independence and individuality of that resident.

Residents may be billed for items that are included in the Medicaid daily rate, thereby using their small sums of personal needs allowance for goods and services for which it was never intended.

This is a sampling of the kinds of abuses of rights we hear of most frequently at the Law Center. The list could go on for pages.

Despite widespread abuses and the difficulties of resolving many problems informally, residents and their advocates only infrequently use the legal system to vindicate their rights. Many barriers exist to using the system.

BARRIERS TO USE OF THE LEGAL SYSTEM TO ENFORCE RIGHTS

Residents and their families often lack information about what their rights are, and may be misinformed by nursing homes. Thus, despite actions by many state governments declaring duration of stay contracts illegal, applicants unaware of those actions may enter into such agreements. We are told that some nursing homes will dissolve the agreements when challenged, but few people have the information to challenge the facilities. The issue may get into the legal system only when the facility sues the individual resident and family to enforce the agreement. See, e.g., *Glengariff* v. *Snook*, Medicare and Medicaid Guide (CCH), paragraph 33,605 (N.Y. Sup. Ct., Nassau County, 1984).

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People seeking admission to a nursing home may also perceive that they have few options, so that they are forced to accept the nursing home's terms regardless of their legality. The lack of adequate community-based long-term care, and widespread discrimination against Medicaid recipients and heavy care patients support this perception.

Once in the facility, residents may be embarrassed by the incidents that give rise to problems, and therefore do not wish to call attention to them. The need for incontinent pads and diapers is one example. States have found facilities double billing—charging both the resident and the Medicaid program—for such items. See, e.g., *Arkansas ex rel. Clinton* v. *Arkansas Nursing Home, Inc.*, No. 78-1103, 12 Clearinghouse Rev. 126 (June 1978) (Clearinghouse No. 24,173) (Ark. Ch., Pulaski County, filed Mar. 20, 1978); State of Tennessee, Comptroller of the Treasury, Audit Report, Kingsport Health Care Center, Inc., Kingsport, Tennessee, April 17, 1984 at 5.

More broadly, residents may fear retaliation for taking action to assert their rights. Residents' isolation from the community, physical distance from or complete lack of family or friends, and near total dependence on the facility for all their needs make this fear very rational. Although some attorneys believe that residents may actually receive better care and attention during litigation because of closer scrutiny of the situation by attorneys for both sides and by the judge, it is often difficult to persuade residents and their familes of this possibility.

In addition to the reluctance of residents to assert their rights, other barriers exist.

Attorneys, ombudsmen and other advocates are sometimes denied access to facilities, making it impossible for them to educate residents as to their rights and making it difficult for the residents to register their complaints. Few states have access laws that apply to all advocates; even those that do experience problems with advocates trying to enter facilities. See, e.g., letter of July 16, 1985 from Anthony S. Kogut, Attorney, Senior Citizens Unit, DeKalb County Legal Aid Bureau, Mt. Clemens, Michigan to Ms. Florence Miers, Division Chief, Licensing and Certification Division, Michigan Department of Health, Lansing, Michigan concerning an alleged violation of Michigan's right of access law, Section 21763, Public Health Code, 1978 P.A. No. 368, as amended. While at least one federal court has found that certain persons in the community have a constitutional right to access to nursing home residents, others have declined to find the state action necessary to make the constitution apply to nominally private entities. See, e.g., *Teitelbaum* v. *Sorenson*, Civ. A. No. 79-199 PHX WEC (D. Ariz. Preliminary Injunction issued July 3, 1979) (Company town and nexus doctrines support a finding of state action; a constitutional right to access exists.) *Contra, Cape Cod Nursing Home Council* v. *Rambling Rose Rest Home*, 667 F.2d 238 (1st Cir. 1981); *Taylor* v. *St. Clair*, 685 F.2d 982 (5th Cir. 1982)

Even where access is not a problem, the general unavailability of attorneys knowledgeable about nursing home residents' issues makes legal solutions unlikely. (See, e.g., *Klein* v. *Mathews*, 470 F.Supp. 1005 (D. N.J. 1977).) Few attorneys in private practice are conversant with the complex body of federal and state public benefits and regulatory law that governs nursing home activities. Most of those who are represent facilities. While in recent years, plaintiffs' personal injury lawyers have begun to be interested in representing nursing home residents, many of their most successful cases are wrongful death actions, too late to help the resident. Moreover, the jury awards and settlements that these attorneys have succeeded in securing are largely based on non-economic damage theories, i.e., pain and suffering, mental anguish and punitive damages. (Few nursing home residents have economic damages, which are generally measures of lost earnings, lost profits or medical expenses.) Major state and federal legislative efforts that purport to deal with the difficulty health care providers have in getting malpractice insurance threaten to cut-off plaintiffs rights to non-economic damages. H.R. 3084, introduced by Congressmen Moore and Gephardt, is one such legislative effort.

The attorneys potentially most familiar with the laws relating to nursing home residents are legal services attorneys. However, most legal services field program attorneys are swamped by the problems of clients who come to their offices; they have little time to ride circuit to area nursing homes, only to be denied access or met with reluctance on the part of the resident to pursue a claim.

Other barriers to legal action exist. Because of the general dearth of litigation to enforce nursing home residents' rights, and because most cases are settled, only a small body of case law exists. While many legal theories have been raised in litigation, few have been ruled on by courts. The few courts that have ruled on such important threshold issues as whether the Medicaid statute affords an implied private right of action by a Medicaid recipient against a nursing home are divided on the answer. See, e.g., *Berry* v. *First Healthcare Corp.*, Medicare and Medicaid Guide

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(CCH) ¶ 28,693 (No. 77-208, D. N.H. Oct. 26, 1977) (the statute does imply a private right of action); contra, *Stewart* v. *Bernstein*, No. 84-2352 (5th Cir., Sept. 3, 1985).

In the arena of public enforcement, especially through the survey and certification system undertaken by most state health departments, residents rights are often difficult to enforce because in federal regulations, they are only one standard of one condition of participation. Thus, a violation of residents' rights may not appear significant enough to a surveyor to sanction a facility.

SUCCESSFUL USE OF THE LEGAL SYSTEM

Despite these apparently insurmountable barriers to legal action, successful suits have been pursued by and on behalf of nursing home residents to protect and enforce their rights.

The reluctance of residents to come forward as plaintiffs can be overcome by various methods of protecting their identity. One possibility is to proceed anonymously, replacing the plaintiff's name with a pseudonym. Use of pseudonyms has generally been accepted by courts in cases involving reproductive rights, homosexuality, transsexuality, illigitimacy and mental illness. A number of courts have accepted it for nursing home cases. See, e.g., *Resident* v. *Emmanual Family Training Center, Inc.*, C.A. No. 78-477, Medicare and Medicaid Guide (CCH) ¶ 29,098 (N.D. Ohio, May 28, 1978); *Patient Martha* v. *Colonial Crest Nursing Centers, Inc.*, Civ. A. No. 1P 79-343-C (S.D. Ind., filed Apr. 17, 1979), 13 Clearinghouse No. 26,889); *A.P. (Anonymous Patient)* v. *Abbey Nursing Home, Inc.*, C.A. No. C78-1340 (N.D. Ohio, Feb. 18, 1981), 15 *Clearinghouse Rev.* 521-22 (Oct. 1981) (Clearinghouse No. 31, 370); *Resident* v. *Chester Extended Care Center*, No. 81-06307 15 *Clearinghouse Rev.* 372 (Aug.-Sept. 1981) (Clearinghouse No. 31,158) (Pa. C.P. Delaware County, filed May 7, 1981.)

A second way to protect residents' identity is to seek class certification. A class action requires only one named plaintiff, and that plaintiff can proceed anonymously. In *Resident* v. *Emmanual Family Training Center, Inc.* referred to above, a class was certified based, in part, on the "lack of knowledge and sophistification of the proposed class members and their need for protection" and "the reluctance of class members to bring individual actions against their employer, creditor, or other person with power to take reprisals against proposed class members." *Resident* v. *Emmanual Family Training Center, Inc., supra*, at 9963. The federal rule requirement of commonality was satisfied because the violations alleged in the complaint applied to all residents of the facility and were not facts peculiar to the named plaintiff.

A third method of protecting residents is to bring suit using an organizational plaintiff. An organization can sue either as a representative of its members, or in its own capacity. In the former case, it must allege that it has members who are affected by the complained-of-actions of the defendant. In the latter instance, it must show how its own organizational goals are thwarted by the defendant's practices. This type of a suit has great potential for protecting nursing home residents rights due to the large number of resident, family and other advocacy organization, but is of limited applicability for legal services attorneys because of federal restrictions on the groups such attorneys can represent.

As mentioned earlier, personal injury actions and tort actions generally are becoming more frequent in the nursing home area. Evidence of private bar interest includes special nursing home litigation group meetings at the 1983 and 1985 annual conventions of the Association of Trial Lawyers of America. A recent issue of that organization's publication, TRIAL, contained an article on the subject by a nursing home plaintiff's attorney. Tort claims range from wrongful death to misuse of resident funds to conversion of residents' personal property. One case, alleging the theft—or conversion—of several pairs of socks, resulted in the replacement of the socks and the provison to residents of lock boxes to protect their possessions. *Strebe and Day* v. *Lafayette Healthcare Center, ARA Services, Inc. and HealthCare Management, Inc.*, Cause No. S-60-81 (Sup. Ct. Tippecanoe County, Ind. filed 2/4/81) While such a result can seem trivial and insignificant to those of us who can protect a whole houseful of possessions by the turn of a key, it is important for residents who daily must worry about the theft of their very few treasures.

In the case of the lost socks, a real economic injury can be alleged. This is also true of cases alleging misappropriation of residents' funds. Many residents' rights violations, however, do not necessarily include economic loss. A resident who is old, frail, and suffering from multiple chronic conditions, and whose care is paid for by Medicaid will not have lost earnings or out of pocket medical expenses to claim. Nevertheless, if the facility has violated her rights, especially by abuse or neglect with respect to care and treatment, she should be able to get some redress. Juries

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have been sufficiently outraged by nursing home conduct to award substantial punitive damages against defendant facilities. See, e.g., *Harmon* v. *Glisan Care Center, Inc. and Dennis D. Asby, M.D.*, Case No. A8111-07086 (Or., Multnomah County, Jury verdict Aug. 6, 1982) This avenue of redress should not be foreclosed in the effort to remedy other problems in the area of medical malpractice.

In addition to private bar and legal services attorneys representing nursing home residents, several state Attorneys General have acted under state consumer protection laws and other legal theories to protect nursing home residents. In the past, the two most active Attorneys General offices were in Massachusetts and Texas. Those offices successfuliy litigated issues of access to facilities, quality of care and theft of funds. See, e.g., *Commonwealth of Massachusetts* v. *Q.T. Service Inc., d/d/a Harvard Manor Nursing Home, et al.*, C.A. No. 78-564 (Sup. Ct., filed Jan. 31, 1978) (alleging denial of access); *Commonwealth of Massachusetts* v. *Almeida*, C.A. No. 6183 (Sup. Ct.) (alleging misuse of personal needs allowance); *Bellotti* v. *Heritage Hill at Newton Retirement and Convalescent Home, Inc.*, C.A. No. 78-4855 (Sup. Ct., Middlesex County, filed Sept. 14, 1978) (alleging resident abuse); *State of Texas* v. *Southwest Mediplex*, No. 271,587 (Dist. Ct., Tavis County, Texas, 147th Jud. Dist., filed Feb. 23, 1978); *State of Texas* v. *Forest Manor Nursing Home*, No. 77-855H (Dist. Ct., Dallas County, 160th Jud. Dist. Filed Aug. 1977) both Texas cases allege resident abuse). More recently other Attorneys General, notably from Illinois and a few other states, have become involved. Their services are a welcome addition to the arsenal for protecting residents. More should be encouraged to get involved.

Separate from the consumer protection units in the states are the Medicaid Fraud Control Units. While a few Fraud Control Units have been aggressive in protecting residents and their funds, many concentrate their resources on investigations and prosecutions of Medicaid providers engaged in financial fraud. These units are an as yet unrealized source of protection for residents.

A few states—Wisconsin, Texas and Michigan—have taken criminal action against nursing homes for abuses against residents with limited success. An initially successful Wisconsion prosecution for homicide by reckless conduct was ultimately reversed, *State* v. *Serebin*, No. 82-232-CR (Wisc. Ct. of Appeal, July 26, 1983). More recently, a Michigan court refused to bind over a nursing home charged with soliciting a bribe in connection with a duration of stay contract. *People* v. *Westland Convalescent Center, Ind.*, Criminal Compl. No. 85-00753-FY (Dist. Ct., 54-A 2d District, filed May 1, 1985). The State of Texas case, alleging murder by the Autumn Hills Convalescent Centers, Inc. and various of its Directors and employees, is scheduled to go to trial shortly. While criminal prosecutions have been few and not very succaessful to date, they should not be abandoned as part of the enforcement system.

RECOMMENDATIONS

At the Chairman's request, we recommend a number of actions the federal government and state governments can take to improve the legal climate for vindicating residents rights.

1. Elevate residents rights to a Condition of Participation.
2. Amend the Medicaid law to expressly include a private right of action for recipients against Medicaid providers.
3. Enact legislation ensuring access by attorneys and other advocates to institutions where vulnerable people reside.
4. Encourage funding in legal services field programs for specialists to represent nursing home residents, and liberalize regulations concerning group representation.
5. Discourage malpractice-related reforms that would deny access to courts to pursue claims for non-economic damages.
6. Encourage clear direction from the Health Care Financing Administration concerning its interpretations of federal law.
7. Encourage the development and widespread dissemination of programs to educate nursing home residents, their families, the communities and the facilities about residents rights.
8. Encourage greater national support of the Long Term Care Ombudsman program in the Administration on Aging.
9. Encourage the involvement of state Attorneys General in actions to enforce residents rights.
10. Encourage an expansive interpretation of the mandate of Medicaid Fraud agencies to pursue problems of resident abuse.

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CONCLUSION

The legal system does provide recourse for protecting nursing home residents. While the barriers are substantial, they are not insurmountable. Changes in the system suggested in this testimony could improve residents ability to use the system.

Thank you for this opportunity to testify.

Mr. PEPPER. Thank you very much.

Ms. NEMORE. Thank you very much.

Mr. PEPPER. Ms. Holder. Ms. Holder is another of the outstanding qualified witnesses we have here. She is the executive director of the National Citizens Coalition for Nursing Home Reform, and I find myself in the embarrassing situation of having to leave. I have got to meet a very important group over at the Capitol at 2:30.

Like all the people who are hungry here, I would like to get a bowl of soup, at least, before I get over there. We have got four more witnesses to hear, and I will just have to ask you all to observe what we call the 5-minute rule that they impose on us in the House sometimes.

If you could give me a summary and file any statements you would like to file, I will have to do the same thing with the other four witnesses that are coming right after this panel.

So, if you will give us a summary of your statement, Ms. Holder, we will appreciate it.

STATEMENT OF ELMA HOLDER, EXECUTIVE DIRECTOR, NATIONAL CITIZENS COALITION FOR NURSING HOME REFORM, WASHINGTON, DC

Ms. HOLDER. OK. I will certainly try to do that.

First, I want to thank you very much for holding this hearing. It is the kind of hearing that——

Mr. PEPPER. Excuse me. We would like to keep in touch with you, if you are representing these people that we are talking about; see if we can—I mean, from time to time, let you make recommendations to us.

Ms. HOLDER. Sure. Well, we need this kind of boost and we need this kind of kick in the pants as well, all of us, consumers and providers and regulatory people, because the public has to be reminded of these significant problems and what needs to be done about them.

So, this hearing is, in itself, a movement in the right direction. Let me just emphasize a couple of things.

I am glad that you are going over to sit down and talk with Secretary Heckler. However, I do not have the same kind of confidence as you do that she cares as much about the nursing home residences as we would like her to.

So, I would like for you to remind her, when you do sit down with her, that at one point in time in history in our country, we did have residents' rights elevated to a condition of participation in Federal regulations. Unfortunately, in 1981, when the new administration came in, those particularly important regulations were rescinded as one of the first official acts of the new administration. So, if you can remind her of that and give her the golden opportunity to recoup that major loss, we would be very grateful.

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The other thing that I want you to do is to do everything you can to work with us to kick the Administration on the Aging in the pants as well, and to get it to offer more support to people around the country who are working to improve the lives of elderly people in nursing homes. They do not give enough support to the long-term ombudsman programs and citizens groups, and they should.

And, last but not least, please work with us continually to go to the Department of Labor, to other national agencies that should be kicked in the pants to get them to do something about the conditions for workers in nursing homes because, in my opinion, unless we do something to move toward that direction, we really are never going to attain quality care and see the residents' rights that we want maintained in nursing homes.

So, thank you once again.

Mr. PEPPER. Well, thank you. You are very kind, Ms. Holder.

Well, all right. I want to tell every one of you who are here today what excellent presentations you have made, how helpful you have been to us, and we hope you will continue to communicate your thought with us in the future.

So, thank you all very much. Anybody who wants to go down to the cafeteria, I will be glad to have you go down with me as soon as we get through. It is right here in this building, and there are not too many places around here where you can get lunch. I am sorry to have kept you hungry—like some of the patients in the nursing homes.

Thank you. Neil, I am so glad to have seen you.

[Brief recess.]

Mr. PEPPER. The committee will come to order.

Our next witness will be Thomas Morford, Deputy Director, Health Standards and Quality Bureau, U.S. Health Care Financing Administration.

Mr. Morford.

STATEMENT OF THOMAS MORFORD, DEPUTY DIRECTOR, HEALTH STANDARDS AND QUALITY BUREAU, U.S. HEALTH CARE FINANCING ADMINISTRATION

Mr. MORFORD. We all recognize as fact that our nursing home residents are totally dependent on the facility for their physical and mental well-being as well as their basic human rights. We play our role in this effort by, first, establishing Federal requirements, and second, mandating the process to enforce these requirements.

Let me just very briefly address the requirements themselves. They are both in the law and, in more detail, in Federal regulations. These requirements range from the facilities' management and organization to staff qualifications; from physical plant aspects such as fire safety; as well as services provided to the patient.

We think we have good requirements. We think that we have helped bring the nursing home industry a long way by vigorously enforcing these requirements. But we are not satisfied with the requirements. We have not been satisfied with them for a number of years.

As you well know, it is very difficult to change things that are consistently in controversy, even when well-intentioned. Conse-

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quently, in 1983 we funded a study by the Institute of Medicine of the National Academy of Sciences in the amount of $1.5 million to advise us on what kinds of Federal requirements we should have; what changes we should make; what the specific relationships between the Federal and State Governments should be; and what kinds of actions we can take to improve the requirements. We are looking forward to getting the recommendations, which are expected by the end of November; and I hope that they contain recommendations on statutory, regulatory, and internal changes that we can make.

As far as the process goes, we need enforcement standards. For both the Medicare and Medicaid programs, we are in a partnership with the States. Under Medicare, the Federal Government makes the decision as to whether or not the facilities comply with Federal standards. The Medicaid statute specifically requires that the States make that certification. We have about 3,000 inspectors employed by the State health departments to inspect for us under Medicare and we also fund Medicaid inspections.

In addition, we exercise our Federal oversight responsibilities by reviewing directly the staff at the facilities and making determinations as to whether or not the facility is in compliance, and whether the States have done their job.

You have heard characterized, I think inappropriately, the Amos and Andy approach about whose responsibility it is. I do not view it that way at all. We take the responsibility very seriously, and, in fact, some States are getting some sizable disallowances because they have not performed their enforcement functions appropriately.

I think we can attest to the fact of how seriously we take this responsibility. By the same token, improvements can be made in this as well as any other process and, consequently, we began funding demonstrations as early as 1978. We think we have come up with a better surveying tool; a better tool to give these surveyors that go into the nursing homes help in making judgments about whether or not facilities are in compliance, and whether or not the patients are getting the good care that we are paying for. I might add that we have developed this in concert not only with the nursing home industry, but with considerable input from some of the people who represent the patients—the National Coalition for Nursing Home Reform, State governments, and other national patient advocate organizations.

We are very optimistic. We want to improve the process. We want to take away the focus on the facilities and the physical plant, and instead stress more patient outcomes, such as the condition of the patients. We want the surveyors to actually look harder at the kind of care being rendered, and the kinds of services these patients are getting.

We are planning to publish a proposed rule by the end of October, in which we will explain the new survey process. We will be looking forward to hearing public comments, which, I hope, will be favorable since it was developed with a broad national consensus. We will make whatever modifications we need to make and, hopefully, implement it in the next calendar year.

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Mr. PEPPER. Mr. Morford, is your agency under Health and Human Services?

Mr. MORFORD. Yes, it is.

Mr. PEPPER. Well, I haven't time to explore your statement with you in detail, but we will examine it, and then discuss the matter at greater length with your agency. I'm afraid that the bad conditions with 1.5 million—not all, by any means—but millions of nursing homes somehow or other defeat your edicts. And I'm not opposed to you as you can see. All of you do a fairly creditable job, in all you attempt to do.

Mr. MORFORD. Mr. Chairman, I would welcome further discussion at any time. I think we do not do a perfect job; we do miss some things. We do the best we can.

[The prepared statement of Mr. Morford follows:]

PREPARED STATEMENT OF THOMAS G. MORFORD, DEPUTY DIRECTOR, HEALTH STANDARDS AND QUALITY BUREAU, HEALTH CARE FINANCING ADMINISTRATION

Mr. Chairman and members of the Subcommittee: I would like to thank you for this opportunity to describe the role of the Health Care Financing Administration (HCFA) in assuring the health, safety and rights of Medicare and Medicaid beneficiaries in nursing home facilities. With the help and cooperation of the States and, indeed, the care and concern of our beneficiaries' families, we are able to use several tools to monitor and correct problems in nursing home care delivery which directly affect the well-being of our elderly and disabled beneficiaries.

CHARACTERISTICS OF THE MEDICARE AND MEDICAID NURSING HOME POPULATION

The population of individuals we cover in nursing homes is one that uniquely deserves the full protection and legal remedies of the Federal government. Most of our nursing home beneficiaries are poor, with severe physical and mental disabilities that require their institutionalization for long periods of time.

The fact is that our institutionalized beneficiary is almost totally dependent on the staff of the nursing home for his physical and mental well-being, including the protection of his basic human rights.

To assure that these protections are afforded our beneficiaries, we work with the States to enforce Federal conditions of participation (for skilled nursing facilities (SNFs)) and standards (for intermediate care facilities (ICFs)). These requirements are based in statute and further enumerated in regulations. They address not only the facility's management and organization, environment, and fire safety but also the professional care and services the facility provides in order to meet the total needs of the patients (i.e., the patients' physical, medical and psychosocial needs). We also rely on the input of patients' family members to assure that high standards are maintained.

INSTITUTE OF MEDICINE STUDY OF NURSING HOME REGULATIONS

Mr. Chairman, as you and the Subcommittee are aware, these regulatory requirements have in the past been the subject of much review and proposed revision.

To help deal with these issues in an objective manner, in October 1983, we funded the Institute of Medicine of the National Academy of Sciences to study nursing home regulations. This $1.5 million study is scheduled to end on November 30, 1985.

The report will provide recommendations in three areas: objectives that nursing home regulations should seek to achieve: effectiveness of regulations in assuring quality of care; and relationships of Federal and State Governments in the regulatory process.

In each of these areas, the report will discuss modifications to the current regulations in terms of both short and long-range objectives. More specifically, the Institute has made a substantial effort to examine the area of patients' rights and the role of advocates in assuring patients' rights. We shall be carefully reviewing their comments and recommendations to determine what changes we can make within our own system without awaiting statutory changes.

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TOOLS TO MONITOR AND CORRECT PROBLEMS—I. STATE AND FEDERAL SURVEYS OF THE CONDITIONS OF PARTICIPATION/STANDARDS

I would now like to explain in some detail how we monitor a nursing home's compliance with our requirements.

HCFA contracts with a State to certify, through a "State survey agency" (SAs)—usually the State Health Department—that a nursing home facility meets the Federal conditions of participation and standards.

The process followed by SAs is referred to as the "Survey and certification process." This process is established by law, implemented and enforced by regulations, and interpreted in procedural requirements set forth in two manuals which contain detailed procedures that must be followed by the State and Federal agencies involved in the survey and certification process.

State agency personnel perform initial surveys and periodic resurveys of nursing homes at least annually. These surveys: assess the extent and degree to which each facility is in compliance with the regulatory requirements; and obtain an overall evaluation of a facility's performance and effectiveness in rendering high quality and safe patient care.

Surveyors may make additional unannounced visits between regular visits to determine the status of a previously identified problem or to investigate complaints.

Surveyors use a survey report form to record observations, facts, events, and judgments. Review of paperwork as well as observation and interview of patients and staff is stressed in the survey manuals. Surveyors use the information presented in the manuals and survey procedures that accompany the regulations to determine the presence or absence of quality of care (physician, nursing, social rehabilitation, activities and dietetic services).

Identified problems can result in the execution of a statement of deficiencies for which the facility must submit a written plan of correction. This information is the basis for conducting follow-up or monitoring activities to ascertain progress and assist the facility in carrying out its care requirements. If the facility has more serious compliance problems, it is terminated from the Medicare and/or Medicaid program. While terminated is the last resort, we will not hesitate to exercise our authority and terminate facilities.

As part of its role in overseeing the operation of the survey process, CFA conducts Federal onsite surveys through its ten Regional Offices of a sample of all types of facilities to determine the extent that Senate survey agencies accurately identify facility deficiencies. When HCFA reviews certification of facilities that participate only in Medicaid, it is referred to as "look behind," i.e., a look behind of the State review. This is special authority Congress gave the Secretary to make independent determinations of facilities compliance with Federal requirements.

II. INSPECTION OF CARE—MEDICAID INTERMEDIATE CARE FACILITIES

The inspection of care program is administered by each State to determine the extent that quality of care and services are being provided in facilities that participate in the Medicaid program. The inspection team must inspect the care and services provided to each recipient in the facility at least annually.

The team determines in its inspection if the services available are adequate to: meet the health, rehabilitative, and social needs of each recipient; and promote the recipient's maximum physical, mental, and psychosocial functioning.

The second activity of inspections of care is to evaluate the appropriateness of placement. Inspections of care include a review of each recipient's medical record and direct observation of and interview with each resident. A report is submitted to the State, which must take corrective action as needed.

III. PATIENT CARE AND SERVICES (PACS) TOOL

The current survey system, which has been in effect since 1974, was aimed at the many shortcomings in nursing home care that became evident in the late 1960s and early 1970s. The process focuses on structure, e.g., buildings and written policies, on the assumption that if certain structures are present and properly deployed, the desired outcome—high quality care—will be attained. However, it is also important to emphasize the components of the survey process that deal with patient care.

Beginning in 1978, the Department approved a number of demonstrations and experiments with modified survey processes that would combine survey and inspections of care functions to focus on actual care rather than structural requirements. Each demonstration or experiment sought to develop methods and indicators that would reveal the provisions of quality care by a facility.

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In 1982, HCFA began to devise a new survey tool, based on the results of the demonstrations and experiments, which is commonly referred to as the Patient Care and Services (PaCS) tool.

PaCS has two key features: first, it is a resident-centered approach. It provides a more valid estimate of the quality of care furnished by the facility. By bringing surveyors face-to-face with a representative sample of patients or residents, it enables surveyors to more accurately identify their needs and problems, and subsequently, to determine how well care is provided to meet these needs.

Second, by requiring surveyors to follow specific procedures and to review according to a specified checklist, it achieves greater consistency in survey methods and findings.

Although it does not examine each regulatory requirement that is provided on the traditional survey form, a PaCS survey represents a complete survey. Facilities are still required to be in continuous compliance with all regulations in order to be certified. The PaCS survey form includes components of the 18 SNF conditions of participation—those that most directly affect the health, safety and well-being of patients or residents—and an equivalent selection from the ICF standards. Evaluation of the physical environment continues to be a major component of the survey process, but the most innovative PaCS components are the three activities that focus on a sample of the patients or residents: indepth review of furnished care through observation, interview and record review; evaluation of meals, dining and eating assistance; and evaluation of drug administration.

As a result of these reviews of patients and staff, a surveyor can identify patterns and areas where the facility appears to have problems in addressing and providing care. The surveyor can then determine, based on the nature and number of these findings, whether deficiences exist and discuss them with facility staff.

We are currently testing this new patient-oriented survey process on a limited basis in all States. We are impressed with the results which have shown that: use of the PaCS process increases the number of patient-oriented findings; there was an increase in the severity of findings from the PaCS process; and nursing home administrators were favorably impressed with the PaCS process because it focused on information about patient care.

A great deal of the PaCS effort has been made possible by the full cooperation of consumer advocates, the nursing home industry and representatives of State governments. In fact, the continuing support of all these groups and their endorsement of our actions has given us confidence that we have indeed taken a major step toward improving our assessment of care rendered in nursing homes. We are now preparing a Notice of Proposed Rule-Making on the PaCS tool and hope to implement PaCS early next year after we consider public comments on the revised survey process.

In sum, Mr. Chairman, we are fully committed to protecting our elderly and sick who reside in nursing homes. I think this commitment is clearly evidenced by the work we have done to date, but, more importantly, by the fact that we are continuing to strive for improvements in both our requirements and enforcement systems.

Mr. PEPPER. Well, thank you for coming here today. We will be in touch with you and the Secretary about some possible discussion in the matter of what you are doing and maybe what will be best for you to try to do in the future.

Mr. MORFORD. Thank you.

Mr. PEPPER. Now, will Mr. Goldberg, executive vice president of the American Association of Homes for the Aging come forward? Is he here? And Mr. Paul Willging, Ph.D., deputy executive vice president, American Health Care Association. And Barbara Jameson, executive director, National Association of Residential Care Facilities.

You are all associated with the nursing home industry. Well, I want to tell all the ladies and gentlemen that what we say here is not in any sense of the word a condemnation of the nursing home industry. This is a great industry, with many wonderful people.

We have seen, however, many sad cases. I think there ought to be some critical examination as to whether there should be some fairness. How much of the revenue derived from those institutions should go into the operation of the institution, and how much of it

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should be profit? Maybe not too much rigidity, but there might be some maximum or something. I want the industry to get a fair profit.

But I do not want the industry to get an excess profit by hiring incompetent people who give inadequate treatment to human beings who are in a weak period of their lives, as elderly and often ill people are. Now, those are principles that I think we would all agree to.

Well, I'm going to have to go, but you go right ahead. I'm going to start off with Mr. Goldberg. Mr. Goldberg, if you and you other ladies and gentlemen will give us a summary of your statement, we'll appreciate it. But we will insert the whole statement, if you've got a written statement, in the record. Mr. Goldberg, will you begin.

STATEMENT OF SHELDON GOLDBERG, EXECUTIVE VICE PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGING

Mr. GOLDBERG. Thank you very much, Mr. Chairman. I appreciate your tolerance and your patience. This is a very important subject; critical to the future of the elderly of this country for all of us here.

Allow me to introduce myself. I am Sheldon Goldberg, executive vice president of the American Association of Homes for the Aging. We represent approximately 2,700 long-term care and residential retirement facilities, throughout the country, which on any given day serve approximately 500,000 elderly citizens of this country.

I'd like to make a couple of prefatory remarks if I might. I have a very emotional reaction to what's been said today. As the representatives of solely nonprofit facilities and the countless individuals who serve the elderly in this country: Administrators, perhaps the owners, the boards of trustees, and the staff—all of whom are very, very caring individuals—I fear that many here today will get the wrong impression. They may feel that the care and services they render to the elderly are not appreciated.

So often I hear from HCFA, Health Care Financing Administration, Health and Human Services, State Medicaid agencies, and others, that the not-for-profit homes in this country are inefficient. That they don't do quite as well because their wages are higher and they have higher staff patterns than perhaps in other homes. Because their costs in these areas are higher to some degree, sometimes that is viewed as incompetence, when we're actually investing more in providing care. We are not-for-profit. We do not look primarily at the bottom line. That is not our major consideration. These are communities that have served our country well for over 200 years. Obviously to some degree I feel defensive. But certainly elder use is a very important issue, and one that would be harmful to whitewash. But I do want to recognize the many competent staff that serve the elderly diligently and are very concerned.

I certainly want to indicate very clearly our support for the issues which were developed by the National Coalition of Nursing Home Reform. They told us something we learned a long time ago, that individuals in nursing homes remain that: they are individuals. They have concern for making decisions, for being informed,

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and having their rights protected. These include not only the rights guaranteed by the Constitution of life, liberty, and the pursuit of happiness; but, in the care of the elderly, it also means rights to a quality of life and a quality of care in the environment in which they are residing.

As an association organized for almost 25 years, we published our own bill of rights. We support your bill of rights completely. As a matter of fact, the issues you've raised are those which we have advocated our members follow for a decade. And we have copies for the subcommittee of our bill of rights, which we hope is posted in every not-for-profit member in our organization. We feel it's very important that the elderly know what these rights are.

Further, we've published a number of books, conducted educational training sessions, and taken a leadership role in advocating the important role of residents in decision making and in the formation of resident councils. The residents can come together and collectively voice their views to the owners, or managers, or boards of trustees.

All of our homes are governed by boards of directors—citizens from the community—who serve without compensation. We have asked congressional members and others to come in, look around and spend time in the homes. They may get a sense of the type of care that is provided in the nonprofit homes in this country. We have developed a tool for our member homes to assess the quality of care. And, we urge the trustees, noncompensated individuals from the community; union officials; bankers; housewives; and others to go to the homes and talk to the residents, find out how well they're treated, and what they think of the care that's being provided. These are activities endorsed in the National Coalition for Nursing Home Reform's study.

Without getting into a great deal of detail, because I have included it in my written testimony, I believe, as I think you should as well, that you can have all the regulations in the world and all the surveyors. You can post the surveyors right in the home. But the issues still boil down to issues of economics. Within the environment today—faced with the current administration and very real budget deficits—we are told that the good providers will cut the price of care. For some, that means cutting costs relative to food, staff, or wages. And, that becomes a very crucial issue.

I want to share one thing with you. There has been much discussion of profit. I do not believe that the identification of what profit margins are, or what they should be in terms of operation is the most significant aspect. I do not believe profits for the nursing homes come from operations. The profits in nursing homes come from the real estate side, from buying and selling.

This hearing and past hearings have looked at the profits of nursing homes in this country. It is a scandal that goes back to the very beginning of Medicare and Medicaid. Individuals will move in, buy the real estate, sell the real estate and make their money on the quick deals, the quick fixes, and the quick exchange of dollars that go into real estate. That is not dissimilar today. That is still the truth. We are in a situation, we're finding, where long-term care is a consolidating industry. Literally in this country, we have one company controlling the lives of perhaps 145,000 senior citizens

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under one corporate ownership. Consolidation is growing at an unbelievable and unprecedented rate. By opposing any attempt to reinstitute a system which results in higher medicare or medicaid reimbursement for revalued assets following the change of ownership of nursing homes, this subcommittee and this Congress can deal with this issue right now. One of the concerns we've talked about and want to encourage is long term stability and long-term ownership in this field. As I indicated, our homes are in for the duration. Some of them go back over 200 years. They enter it and they are going to be in from now into the future——

Mr. PEPPER. We could probably try to arrange to give you an opportunity to comment. We thought it would be fair. Ladies and gentlemen, I apologize. A vote is going on up there on the floor. I've got to go up there now. We feel pleased to allow Ms. Cravedi, who's been staff director of our subcommittee for a long time, and done a great job, to sit here. Dr. Willging and Dr. Jameson, I'll be very grateful to you if you would give your testimony to our staff director. And I hope you'll forgive me for having to leave, but I guess we've got too many witnesses, and we're too interested in what they have to say. Here it is, we were supposed to end at noon, and it's 2:15. But we've got some very good testimony. Thank you very much Mr. Goldberg, for your statement.

[The prepared statement of Mr. Goldberg follows:]

PREPARED STATEMENT OF SHELDON GOLDBERG, EXECUTIVE VICE PRESIDENT, AMERICAN ASSOCIATION OF HOMES FOR THE AGING

Mr. Chairman and members of the Subcommittee, I am Sheldon Goldberg, Executive Vice President of the American Association of Homes for the Aging (AAHA). AAHA is the national representative of over 2,600 nonprofit facilities providing health care, housing, and community services to more than 500,000 older Americans across the nation.

On behalf of the Association, I wish to commend the Subcommittee for its investigation of the vitally important issue of protecting rights of elderly residents of long term care facilities. AAHA members share the Subcommittee's concern over continuing reports of neglect or physical abuse of older Americans. We are pleased to have this opportunity to present our views on this issue and to comment briefly on several proposed legislative remedies.

Throughout its 24-year history, AAHA has championed residents' rights. Our members, as nonprofit organizations, share a tradition of charity and community involvement. Over 75 percent of AAHA homes are affiliated with religious organizations, while the remaining are sponsored by private foundations, fraternal organizations, government agencies, unions, and community groups. Our members' concern with the well-being of their residents is reflected in AAHA's philosophy that aging is a natural process which should not limit or change a person's right to autonomy and to experience life to its fullest. AAHA members are committed to meeting the physical, social, psychological, emotional, and spiritual needs of their residents in a manner which enhances residents' sense of self-worth and dignity and allows them to function at their highest degree of independence.

QUALITY OF LIFE

The Association and its members recognize that residents' rights include the protection of civil liberties and legal rights basic to all Americans, particularly the right to be free from physical, emotional or financial abuse. We believe, however, that residents' rights go beyond these basic guarantees and include the concepts of quality of care and quality of life.

We appreciate the work done by the National Citizens' Coalition for Nursing Home Reform in assessing residents' perceptions about their care. Our members were pleased to participate in this effort and reassured to find that the importance we place on quality care was recognized and confirmed by the residents surveyed. The study found that residents' primary concern dealt with the size, attitude, and

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quality of the staff. It was also clear that the size and privacy of rooms, food, and activities were important. Residents want to have choices about their daily lives and to be involved in decision-making. In short, they want their needs as total human beings to be recognized and considered.

In 1966, only a short time after AAHA was founded, we published a book, the "Social Components of Care," identifying those physical or program arrangements of nursing homes which allow and encourage older people to realize themselves fully as individuals with personal dignity and as members of the home's community, as well as the larger community in which the home is located. And, we have continued to provide nursing home administrators and staffs with publications to enhance their ability to meet these goals. These publications include "Resident Decision-Making in Homes for the Aging," a step-by-step guide to starting a resident council or improving existing ones, and "Quality of Life Assessment: A Profile of Resident Satisfaction," a workbook to assist staff in determining residents' values, preferences, and perceptions of the facility to enable the staff to adapt or improve current methods of creating a quality living environment.

Through publications and continuing education, the Association has worked to foster the attitudes, motivation, training, and commitment which are the foundation of quality care for elderly residents of intermediate and skilled nursing facilities. However, nursing homes exist in a highly regulated environment. Dozens of agencies can be involved in the network of regulations, licensing, and oversight—federal, state and local governing bodies, the court system, and community advocacy groups all can play a role. Residents' rights of autonomy and privacy often have to be balanced with regulations designed to protect all of those living in the nursing home. For example, a spouse visiting the nursing home may desire privacy, however the life-safety code prohibits locks on doors.

RESIDENTS' BILL OF RIGHTS

Because of the varying, and sometimes conflicting expectations, needs, and requirements involved in administering nursing homes, AAHA's membership adopted in 1975 (prior to enactment of federal standards) a "Bill of Rights" to emphasize that residents are entitled to informed and confidential health care. These include rights: to full information regarding medical condition, diagnosis and treatment (unless medically contraindicated); to prompt care by qualified and competent personnel; to privacy during care and confidentiality of all medical records consistent with adequate treatment; to retain a personal, private physician for purposes of consultation with staff doctors; to be free of physical or chemical restraint, except when medically authorized; and to give or withhold informed consent for non-emergency treatment after the implications of that choice have been explained.

While AAHA members believe these rights are basic, we also believe that each resident must be permitted to exercise inherent human rights that contribute to the totality of individual well-being and self-respect. Therefore, AAHA's Bill of Rights included rights: to religious and civil liberties; to manage personal finances; to have suggestions considered by staff and administrators through media such as residents' councils and to present grievances without fear of reprisal; to safe and secure physical accommodations and to an aesthetically tasteful environment; to privacy and confidential communication by mail and telephone, including the right to confidential communication with an attorney; and to the widest possible freedom of choice and decision consistent with the standards, rights, and obligations of the home.

In addition to assisting its member. formulate resident's rights, AAHA was active in early suport of federal efforts to assure the protection of these rights. During the 1970s the Association urged the Administration on Aging to direct its ombudsman program to assist in developing resident councils. AAHA also supported efforts to include residents' rights in the Medicare and Medicaid Conditions of Participation for skilled and intermediate nursing facilities.

ELDER ABUSE

Despite the best efforts of nursing home administrators and regulatory officials, it is clear that abuse or neglect of nursing home residents occurs. Research indicates that a majority of elder abuse is caused by persons providing long term home care for dependent older persons and is the result of stress. Stress is, undoubtedly, a contributing factor in the abuse or neglect that takes place in institutions. The majority of day-to-day care of nursing home residents is provided by nursing aides. These staff members tend to have the least training prior to assuming their positions. Many are ill-prepared to cope with the heavy care needs of a large segment of the population served by nursing homes; half of whom have cognitive failure or mental

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disorder as a primary or secondary diagnosis. Some nursing home aides become demoralized or frustrated by the continuing burden associated with caring for a highly dependent adult. Their stress may be further exacerbated by the fact that they are among the lowest paid staff in nursing homes, and, not surprisingly, their turnover rates are the highest.

Of course, abusive treatment of vulnerable elderly persons can never be justified. However, an understanding of the sources of these actions can lead to identifying effective solutions.

THE FEDERAL ROLE

The federal role in protecting nursing home residents and assuring quality care can not be minimized. Through its policies for surveying and certifying Medicare and Medicaid long term care facilities, the federal government plays a central role in oversight of the care received. AAHA was pleased to participate with the Institute of Medicine in its study of nursing home regulations and with the Health Care Financing Administration's testing of an outcome-oriented patient assessment survey tool. We are hopeful that the Institute will recommend and HHS will quickly implement a survey process involving nursing home residents as a central component. We also urge that surveyor training and skills be upgraded.

Federal reimbursement practices under the Medicaid and Medicare programs may be the most critical element in assuring quality care to dependent elderly persons, both in long term care facilities and at home. Providing quality nursing care is a result of the competence and motivation of both professional and support staff. Without adequate reimbursement, the requisite number of competent staff can not be hired, trained or retained. A reimbursement system that pays for services at levels below actual cost to providers (as is characteristic of current federal payments) serves to discourage quality care and diminish the possibility of offering residents the broadest options of services and activities.

AAHA urges Congress to reject proposed cuts in Medicaid funding that would further restrict already inadequate reimbursement of nursing homes. Moreover, we urge Congress to expand coverage under the Medicare program to permit reimbursement for nursing services provided in intermediate and skilled nursing facilities. In addition, we urge Congress to review current Medicare cost limits that discourage reimbursement for a broader variety of home health care services, including respite care for severely incapacitated persons receiving care at home.

AAHA further urges Congress to enact several legislative proposals to promote quality care and to assure residents' rights in long term care facilities. One proposal, H.R. 1674, sponsored by Chairman Claude Pepper (D-Fla.) and Representative Mary Rose Oakar (D-Ohio), would create a national center on elder abuse to disseminate information and fund state programs on the prevention and treatment of abuse to elderly persons. The second proposal, H.R. 2829, also sponsored by Chairman Pepper, seeks to double federal matching funds for state Medicaid Fraud and Abuse Control Units to permit more extensive investigation and prosecution of patient abuse and neglect complaints in Medicaid reimbursed facilities. Both proposals are urgently needed and deserving of support.

COMMERCIALIZATION OF CARE

Even if these measures were enacted and adequate funding provided, AAHA believes that residents' rights still might be jeopardized by a changing orientation in the nursing home industry. It is appropriate that the Subcommittee is focusing now on the needs of individuals in nursing homes during this time of increasing commercialization and corporatization of the industry. Currently, there is an annual turnover in nursing home ownership of up to thirty percent, which threatens the stability of the the industry to the detriment of residents and the community. Before 1984, the sale of a facility established a new and significantly higher cost for depreciation and debt services, as assets were revalued upon acquisition at a significantly higher rate. This resulted in higher Medicare and Medicaid reimbursement to new owners without an associated enhancement of the quality of care provided.

AAHA commends Congress for action taken last year limiting this process of revaluating assets under Medicare and Medicaid when homes change ownership. We urge you to strongly oppose a repeal or substantial revision of the law as written, during consideration of reconciliation legislation or at any other time. In addition to helping save federal dollars without adversely affecting resident care, the new law helps discourage rapid turnover of ownership. It also helps slow the consolidation of ownership of the nursing home industry which some experts believe could be domi-

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nated by five to ten proprietary chains as early as 1990, leading to less diversity and freedom of choice for consumers.

Dr. Arnold Relman, editor of the "New England Journal of Medicine," reminds us that, ". . . The professional ideal that medicine [and health care] has always tried to live up to is that of a primary commitment to the welfare of one's patients. Doctors [and other health care professionals] are committed to put the patient's interest before their own and to act as a trustee or an agent for the patient . . . That's what makes it different from a business. . . . There are things—higher education, religious services, police and fire protection and health care—that are not suited to be distributed in a commercial market." AAHA believes that we need to encourage long term ownership, stability, and community involvement of nursing homes, not real estate manipulation or windfall corporate profits.

Tish Sommers, president of the Older Womens League, noted that in all aspects of health care, "We must emphasize that the bottom line is compassion. . . ." AAHA believes the nursing home industry should not be a real estate business. Nursing homes exist to serve the needs of our elderly population and have an obligation to ensure the protection of all their rights.

Ms. CRAVEDI. Dr. Willging.

STATEMENT OF PAUL WILLGING, PH.D., DEPUTY EXECUTIVE VICE PRESIDENT, AMERICAN HEALTH CARE ASSOCIATION

Mr. WILLGING. As requested, I will summarize my remarks and ask that my entire statement be entered in the record. I think I will start by suggesting that I share Mr. Goldberg's concern that in watching this 17-camera hearing on the ABC, CBS, and NBC news, most Americans would come away with the impression that if they or their loved ones need nursing home care, they are likely to face abuse or inadequate care.

That is what concerns me about this kind of a hearing, because I think that frankly we have had problems in the past. Today, through the nursing home industry's own efforts, and to some extent through regulatory agencies, State and Federal, it has made dramatic strides in professionalization and in providing the type of care in almost all homes that Americans have the right to expect.

I do worry about those 1.3 million nursing home employees who have been told today that they are not providing caring services to the elderly. I worry about those Government officials, who have by some witnesses been accused of malfeasence. I worry about the shiver of fear that goes through those Americans who might at some stage need nursing home care. But I think what I worry most about, in listening to the testimony today, is the focus on symptoms, rather than on the cause of the problem.

We have problems in the nursing home industry, there's no question about it. The chairman mentioned one: Most of the care in nursing homes is provided by nurse's aides who are paid an average of $3.40 per hour. Why is that? That is because this industry is largely dependent on the Medicaid Program. In terms of the most recent data provided by the Health Care Finance Administration, there are still 23 States who think they can provide intermediate care for $35 per day or less. There are half a dozen States who think they can provide a day of skilled nursing facility care for $35 or less.

There are in this industry the same laws of economics that pertain to other American industries. You get what you pay for. One may choose to disbelieve that as far as nursing home care is con-

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cerned, but the law of economics has not been repealed in the nursing home industry.

What I did not notice in Mr. Douglas' statement this morning, when he talked about additional enforcement, or the gentleman representing the Hoover Commission when he also talked about additional enforcement is that California did something beyond simply pass another law that addresses only the symptoms of the problem. California recognized the root cause of the problem. In addition to strengthening its enforcement mechanisms the State provided an additional $18 million for the improvement of staffing within nursing homes. They provided for an additional $1.96 per patient day per wage increases, and another $1.18 for additional staff.

California has recognized that enforcement is not the problem alone. One has to ask if this country is willing to pay for the quality of care it demands and has a right to expect from nursing homes. And until this country recognizes that quality care is a right and that quality care has to be paid for, we will unfortunately have isolated instances of abuse.

It is not corporate greed. It is not venality in the nursing home operator, even if the data provided by one representative today were accurate, which it was not. The mythical corporation referred to with its 10- to 14-percent EBIT—a new economic term to me—earnings before interest and taxes, I always assumed interest and taxes were a cost of doing business. I made a call to the president of that corporation following that testimony. That corporation's 1985 profits—profits for me, a dumb country boy from Minnesota, is after you pay all your expenses and you got your revenues left over—is 1.7 percent this year.

Now I would not necessarily agree with the chairman that we need a standard for profit, but I guarantee that if we had a standard for profit in this industry and if it were analogous to the profits of other industries in this country it would be a darn sight higher than 1.7 percent.

We need to ask ourselves, do we as a country demand quality care for our residents in nursing homes? The answer should be, I hope, yes. The second question is, do we as a country desire to pay for that care?

Thank you very much.

[The prepared statement of Mr. Willging follows:]

PREPARED STATEMENT OF PAUL WILLGING, PH.D.

Mr. Chairman and Members of the Subcommittee: I am Paul Willging, Deputy Executive Vice President of the American Health Care Association, the nation's largest nursing home association, representing nearly 9,000 long term care facilities of all types and sponsorship. Collectively our members provide care to over 850,000 residents in a variety of inpatient settings such as nursing homes and residential care facilities.

We appreciate the opportunity to come before you today to briefly talk about resident's rights in long term care facilities. It is impossible to cover such a broad subject adequately in five minutes' time. And so, if you will permit, I would like to describe our Association's activities and initiatives with regard to patients' rights and to highlight several areas that we feel are problems with suggestions for improvement.

I would like to state at the outset that the American Health Care Association firmly believes that long term care facilities should have an active program that

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promotes the spirit of residents' rights. The basic philosophy of the facility and each department should reflect concern for residents' dignity and individuality. Staff should be instructed not only in the specifics of the patients' rights, but also in respectful, courteous methods of delivering services and in techniques for encouraging residents to exercise their rights. We deplore any instance of patient neglect or abuse in any long term care facility. With over one million employees in our nation's nursing homes, however, we cannot guarantee that serious problems will not occur on occasion.

As an association, we believe that our role is one of education and dissemination of pertinent materials. Our goal is to assist all nursing home employees, as well as other interested parties in dealing with the difficult problems they may face in their day to day relationships with the 1.5 million nursing home patients.

Patients' rights issues were given high priority in our association a number of years ago. We have devoted significant resources and staff time in developing materials and training programs for all who are concerned. Our staff has participated in numerous seminars and are available as resources to our 49 state affiliates. Every one of our annual convention programs has had educational sessions on patients' rights issues, and our state affiliates have been active in a similar fashion.

Many of the serious problems which have existed in the past on patients' rights issues can be traced to a lack of understanding of the issues involved and to an insufficient sensitivity on the part of the nursing home staff to the needs of the patients. The American Health Care Association felt that the best way to address this issue was to embark on an education program to reach not only our 9,000 members, but also the aging network of concerned citizens and the patients and families themselves. To that end we have published an extensive amount of materials such as:

Pamphlets on "Patients Rights, Health Care Decisionmaking," and "Public Access." These pamphlets are available free on request and are policy statements which have been adopted by our Board of Directors.

"Decisionmaking and Patients' Rights," the entire May 1985 issue of our "AHCA Journal" was devoted to patients' rights issues with articles contributed by ombudsmen, consumer advocates and providers. In addition to being sent to our 9,000 members, copies of the Journal were distributed, with the assistance of the Administration on Aging, to the entire network of aging organizations, including state ombudsmen, and area agencies on aging.

"Residents' Rights—A Manual for Long Term Care Facility Administrators"—an 83-page manual for administrators and supervisors in long term care facilities which has also been used extensively by ombudsmen in the training of volunteers and by advocacy groups. Chapters covered include "Interpreting the Residents' Bill of Rights," "Discrimination in Admission and Care", "Staff Training", and "Advocacy in the Nursing Home".

"Questionably Competent Long Term Care Residents. Problems and Possible Solutions"—a 48-page report developed in 1982 by a multidisciplinary committee convened by AHCA, has become a desk reference for those interested and involved in this issue.

QUEST FOR QUALITY

For the past four years, nursing homes across the country have been participating in "Quest for Quality," a self appraisal system developed by AHCA for long term care facilities which covers all aspects of patient services and facility functioning. Nearly 5000 nursing homes are currently using this program. In addition to making sure facilities have all the required policies and procedures related to patients' rights and reviewing all complaints and suggestions, Quest for Quality directs the facility's management to walk around the facility, to look for and listen for examples of how patients' rights are either being promoted or denied: Is care taken to protect privacy during bathing? Do resident rooms have unique furnishings and decorations? Are staff members rough with patients or do they treat them with respect? After taking this inventory, a group—which may be made up of residents, families, staff and the administrator—meets to identify problems found, consider why these problems may be occurring, set goals and develop a plan for preventing problems and generally for promoting patients' rights.

I request that these materials be made part of the public record of this hearing.

PATIENTS' RIGHTS—A BALANCING PROCESS

Long term care facilities must consider the interests of many groups and individuals in the day to day provision of services to the elderly. There are patients and residents that have diverse needs. The ability of residents to exercise their rights

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may be constrained by their condition; their rights may be modified by the rights of other residents as individuals and as a group. For example, a resident's right to retain personal possessions may be limited if certain items pose a hazard to other residents.

Members of residents' families may have varying amounts of interest in and involvement with the resident and the facility. Family members have basic rights in areas such as access to information, decision making, freedom of communication, privacy and autonomy. However, the rights of residents and their families must be balanced against each other and against the rights of individual residents and of other residents as a group. Family members are welcome to visit, for example, but a constant crowd in a resident's room could infringe on the privacy of the resident's roommate. As a result, the facility may place restrictions on the number of visitors at one time.

Living in an institutional setting necessitates compromises: patients cannot always have baths and meals whenever they choose. As health care professionals the long term care facility staff must be aware that dependent people, particularly in a group setting, are always at risk of having their individual rights compromised. The balancing of the individual's rights and desires with the requirements of running an efficient facility with perhaps 100 other patients who have the same rights is not simple and the result may not always be "fair."

There are three types of patients who cause the most difficulty in this balancing process:

Competent residents who disagree with certain policies or restrictions imposed for the good of whole group, for example, a resident who wishes to smoke in a public area designated "non-smoking."

Families of competent residents who disagree with what the resident is doing, for example, establishing a relationship in the home with a member of the opposite sex;

Questionably competent residents who have not been adjudicated incompetent. Such patients often refuse treatment or care to their own detriment.

Each of these groups poses its own set of problems and dilemmas for the nursing home. As an example, a nursing home administrator in Wisconsin asks if patients' rights may sometimes jeopardize patients' lives. The problem she raises is that, in the view of some nursing home surveyors, all decisions rest with the resident, regardless of their condition, unless adjudicated incompetent. In theory this may seem logical and appropriate, but in practice it means that a patient may refuse bathing, food, treatment and medications. If we are to believe the statistics, up to 70 percent of the patients in nursing homes have Alzheimer's and related disorders. Typical of these patients, is their refusal to eat or to accept medical treatment. That means that the majority of our patients have the potential for starving themselves or dying for lack of medication. For the nursing home it becomes a question of increasing its liability by allowing patients to do as they please or jeopardizing its licensure by denying the patients their opportunity to exercise their rights.

We fear that the challenge of protecting both the rights and health of nursing home patients will increase greatly, as the average age of the patient population in nursing homes increases and their medical conditions on admission worsen as a result of DRGs.

There are no simple solutions when these issues surface. Our best hope comes in taking a proactive approach in alerting our membership to methods for resolving new problems which may arise, and to make available the necessary material and training programs to enable them to meet the issues head on with sensitivity and intelligence.

ATTITUDE

Perhaps the most challenging aspects of implementing patients' rights in a nursing home is communicating to staff, especially unlicensed personnel, the necessity of demonstrating respect for the dignity and independence of each nursing home patient and resident. Some staff members may come from homes where kindness and respect was not shown to them as they were growing up. In such cases, the facility must take on the responsibility of teaching basic human rights as well as patients' rights. This can be done in a number of ways: by administrators and department heads setting the example of always treating patients and residents respectfully, by those managers treating their staff members with dignity and respect; by making it clear from the first preemployment interview that staff members will be continually evaluated on how they treat patients and that failure to treat patients with respect will lead to dismissal.

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AHCA's new manual on how to be a nurse aide in a nursing home calls for teachers to evaluate nurse aide students not only on how well they perform tasks, but how they treat patients while performing these tsks: do they introduce themselves? Do they explain what they will be doing? Do they answer questions?

In addition, long term care facilities are finding they must offer special support for aides and other staff who must deal with difficult patients and difficult situations. The staff members need help in dealing with sometimes combative, hard to handle and unpleasant residents so that staff never resort to physical or verbal abuse, no matter how they may be provoked.

RESIDENTIAL CARE

Residential care facilities, also known as board and care homes, present a unique problem in assuring that residents are treated with dignity and their rights are observed. Unlike nursing homes and other long term care facilities, the federal government does not establish minimum standards for care or services. The Keys Amendment, Section 1616(e) of the Social Security Act, requires states to establish and enforce standards in facilities where SSI recipients reside. These standards relate to admissions policies, safety, sanitation, and the protection of civil rights. The state must only certify annually that it is in compliance with the amendment.

Thousands of facilities ignore requirements of the Keys Amendment by avoiding licensure. Because SSI payments are made directly to beneficiaries, rather than the facility wherein they reside, states have difficulty identifying those homes which should be licensed and inspected.

Any effort to assure that resident rights and other standards are enforced in residential care facilities where they reside. An aggressive licensing program will be costly to the states since identification of the facilities may require tracking of SSI checks to individuals at the same address. Resources for monitoring and inspection would also have to be increased as well as training for additional surveyors. We believe that the increased costs would be worth the effort. Residents of unlicensed facilities are especially vulnerable to inadequate care. At the least, they deserve the same protections as those in licensed facilities.

In conclusion, I would like to say that we do not pretend to have all the solutions on how to best deal with residents' rights issues. There will unfortunately, continue to be isolated cases of patient abuse and neglect only because the nursing homes and the people who work and live in them are a microcosm of the rest of society. However, the vast majority of the people out there really want to do a good job and we intend to help them in this quest as much as we can.

Ms. CRAVEDI. Thank you.

Now, we'll hear from Dr. Barbara Jameson, who is the executive director, National Association of Residential Care Facilities.

STATEMENT OF BARBARA JAMESON, PH.D., EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF RESIDENTIAL CARE FACILITIES

Ms. JAMESON. In my written testimony I describe the positive results we had in Virginia where the legislators, government officials, residents, and providers were all actively involved in developing the statutes and regulations related to residents rights. This presentation today is in that constructive spirit. The other point I make is that such documents should be called rights and responsibilities. An association such as ours that represents facilities that strive for a homelike environment, and many of our facilities have less than 10 residents, have a special need for everyone to share family responsibilities, especially in how they feel about other residents.

Because this hearing has focused on abuse, I will address two issues that in my experience on the Virginia task force required much thoughtful discussion to arrive at viable resident rights regulations. The first is the definition of abuse. When we are faced with people who have been beaten or sexually violated we know that is

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abuse. But what is the balance point between giving a person helpful support in a geriatric chair and restraining a person for the convenience of staff? Is a person's control over their medical problems abused when they cannot be driven 100 miles to their own doctor? Or even more seriously, when right to die contracts specify no heroic intervention, does that mean the operator cannot give oxygen or resuscitation? Emotional abuse issues have arisen when a resident has one idea on how their room should be arranged and a licensing inspector has another. Where does individual right stop and collective goals begin? Is a resident free to come and go as they please, even if they get lost, if the neighbors and storekeepers complain, or if there are heavily trafficked streets? Our nonmedical homes which encourage independence have some fine lines to walk between rights and realities. Another common disagreement between licensing personnel and home operators is the requirement that residents not be kept in their room to eat. Many home operators feel it really abuses a resident's dignity to make them eat in front of others when a physical condition causes them to be very messy. And many residents claim abuse when they have used their allowance for cigarettes and the operator of the home will not buy them a new dress, a bus ticket, or maybe more cigarettes. This is the daily life in a long-term-care facility.

One of the main fears of home operators is that of being accused falsely of an abuse. Our long-term care facilities have many residents who have delusions or at minimum tell tall tales. Most of our members have at some point been accused of taking money, starving people, or physical or sexual abuse. They know such accusations come with the territory, but it is a great strain. I was talking yesterday to a member who I know really loves her residents and spends long hours and works hard to make their life more meaningful. She told me of a blind lady who had lived with her for a long time. The woman was always saying that one of the staff was sexually handling her. This was not true. One night the lady fell out of bed. She was taken to the hospital where she told the doctor and staff that she had been sexually violated. Of course he reported it. Eventually a doctor who had known the blind lady a long time confirmed that she had had sexual fantasies and our member was cleared. The blind lady is very unhappy in her new home because she misses her old friends and the comfort of the people who knew her and forgave her sometimes funny ways.

This example leads to two points. One is the need for an independent agency to investigate accusations of abuse. There must be professional personnel who can investigate situations and from experience do not jump to conclusions about possible abuse. Our association welcomes the concept of objective arbitrators who help clear up misunderstandings between resident and homeowner. But in our effort to prevent abuse, we must be careful to avoid undue restrictions on the providers or to be so punitive that good providers, and they are the majority, are discouraged from accepting the more difficult residents. The very people who might benefit the most from the patience, understanding, and loving personal care of one of our noninstitutional facilities will be considered too much of a risk. A home operator will prefer a vacancy rather than the threat of lawsuits, redtape, or even more energy drainage.

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You have heard the phrase "Don't throw out the baby with the bath water." We say, "Don't throw out our elderly and disabled with legislative overkill."

[The prepared statement of Ms. Jameson follows:]

PREPARED STATEMENT OF BARBARA JAMESON, PH.D., EXECUTIVE DIRECTOR, NATIONAL ASSOCIATION OF RESIDENTIAL CARE FACILITIES

Members of the committee, I am pleased to be here today as Executive Director of the National Association of Residential Care Facilities, representing the owners and operators of nonmedically focused, licensed residential care for the elderly and disabled. Congressman Pepper, we especially appreciate the interest and concern you have expressed for our level of care.

The facilities we represent are extremely varied, which gives the advantage of offering options to people based on their need and life style. Licensed residential care homes may have only four residents, or be large apartment-like complexes. They may care for only the frail elderly, for young mentally disabled or retarded, or some family-like mix of populations. Whether such homes are large or small, they provide food, shelter, and assistance in daily living to both the affluent and the low income. A large portion of our member homes care for the SSI population, for only $12 to $15 a day. The current actions to raise standards, and the recent influx of residents needing more support, have put a special burden on the resources of those caring for the low income person.

This variation does produce a flexible system whereby an individual should be able to find a facility to meet their needs and life style. However, this variation also causes confusion, even to what such non-medical facilities are called, state by state.

There is also great variation between states as to the extent of regulations and monitoring and the availability of a state supplement for the SSI recipient. There is also great variation between states in the number and type of facilities available in this level of care. We feel one of the rights of our elderly and disabled citizens in the option of non-medical facilities if intensive nursing care is not needed, or if they are unable to remain in their own home or with family members.

The focus today is on residents' rights and on the growing concern of abuse of elderly and disabled people. I would like to offer some materials for your committee's use, relating to the development of statutes and regulations for residential care and to address some of the problems our members have experienced or foresee based on their daily working in these homes.

DEVELOPMENT OF RESIDENT BILL OF RIGHTS

Our association endorses the principle of Residents' Rights. High quality homes, which respect the dignity and personal needs of all residents, reflect well on our whole industry. But we do caution that the development of such Bill of Rights is very complex. What may seem a simple "moral right" or "individual privilege" often has many issues which are not recognized at first glance.

In January of 1983, for example, a Residents' Bill of Rights bill was introduced in the Virginia General Assembly. The bill was tabled for a year to give interested parties more time to study the issue. In a Home for Adults (Virginia's label for licensed board and care type facilities) Advisory Council to the licensing Dept. of Social Services, the provider representatives offered to work with the Dept. of Social Services, to recommend a statute with which both parties could live. The provider associations met with their membership to discuss such legislation. When the legislation was introduced in 1984, it was negotiated and supported by the provider associations, the Dept. of Social Services, and recommendations that had been offered by the Silver Haired Legislature.

After the legislation was passed, a Task Force was formed by the Dept. of Social Services to develop the regulations to carry out the statutes. The Task Force was composed of representatives of providers, consumers, mental health agency staff, aging department staff, and licensing personnel, in addition to legal counsel.

The materials I have turned over to this committee illustrate the care and long hours of work put in to the development of these regulations. Not only was material collected from other states and other sources, but each controversial item was discussed at length. It look some time for the committee members to appreciate each other's perspective and rationale for a point of view. The material shows the analyses, drafts of proposed regulations and criteria, the pros and cons on specific regulations, and the relationship of a Bill of Rights standard to an old regulation.

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An example of a difficult issue is physical restraints. As you know, many geriatric residents use a special chair which gives them support and allows them to sit upright. The use of such chairs has been abused in some facilities, basically restraining people from moving for long periods of time. Although some people seemed to want to do away with the use of geriatric chairs in homes for adults, in fact denial of this supportive device would have been a hardship for many residents who benefit from such support. Regulations were written to put time limits on their daily usage, with continual physician evaluation of their usage.

The right to one's personal physician is also a difficult problem. Homes serving rural areas are especially concerned to not have responsibility for transporting a resident many miles to an old family physician. Another medical issue involves residents' right to decide on what measures can be taken to save their lives. Many elderly persons are now signing right to die contracts, and the intervention lines must be drawn very clearly so a caregiver is not held responsible if they give resuscitation and the elderly person does not want it.

Right to privacy is also a difficult issue. Even though a person should be able to close their door, what happens if they smoke in their room? The president of one of our state associations had a woman catch herself on fire and she became totally immobilized with fear. If the aide had not been in the hall, and if the woman's door had not been open, that life would not have been saved. Privacy also implies the right to intimate relations with other residents. Our caregivers have been given training to foster the idea that elderly residents have needs for touching and other human contacts. When providers have created an environment to encourage such relationships, they are often met with anger by a resident's family. This is one of many areas where gerontologists, trainers, agency staff and others set wonderfully human standards for facilities to meet, and then leave all of the practical problems, interfamily tensions, and daily strain to the caregiver.

Although the process that the Commonwealth of Virginia went through to develop Resident Rights reflect the needs of all parties, the implementation of these regulations is already beginning to produce problems. Regulations were written to cover the development of a service agreement for each resident. Although by itself this can seem like a reasonable obligation to place on a provider, in the task force committee some older consumers said they did not want someone planning their needs, that that invaded their privacy. Provider associations said it would add paper work, which most homes for adults could not absorb. And, again, the small homes caring for low income residents are the least equipped to devise the forms and carry out the process. And yet this is what is being required. Virginia's Residents Rights Bill has not been in operation long enough to have experience with resulting grievance committees or law suits. Our hope is that knowing about negative experiences in other states will minimize some of the destructive results.

RIGHT AND RESPONSIBILITIES

One of the elements that was added to the Virginia effort was the notion that residents also have responsibilities. If such facilities are to be a real home, then residents must treat them as a home and not an over-night hotel. That means that not only does a resident live by rules governing the care of any premises, (one doesn't break up furniture or throw food in the dining room) but that also one tries to work out accommodations with other residents and show the concern and respects one shows in a healthy family.

PROVIDER ABUSE

One issue that is seldomly talked about is the actual physical abuse of care givers. Staff have been attacked by angry or mentally disoriented residents. A former board member of one of the state provider associations was hit on the head by a resident and is now living out his life disabled and brain injured. Other providers have experience with wounds, bruises, broken bones, and other physical punishment.

Although physical abuse is not an everyday happening, some sort of mental abuse is. Providers are almost daily accused of taking someone's money, starving someone, keeping phone calls and letters from people. The majority of such daily complaints are unfounded. If one reviewed the total record of complaints answered by ombudsman, they would find the great majority unfounded, not because there was no evidence, but because many of the people living in such facilities make up stories. One operator told of a mental health worker who had reported her for stealing a client's money. The home operator tried to explain that the client had delusions, but to no

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avail. Eventually she was believed, because the resident then accused the mental health worker of stealing her money.

In my oral testimony I told of one of our members who was accused of sexual abuse. The working through to the truth was a painful experience, and everyone involved lost.

This is one of the most difficult problems in the abuse issue. No one supports ignoring abuse. The problem must be faced. But the general situation is too conducive to misuse of the abuse issue. There are an abundance of residents who do not tell the truth to get attention; who cannot remember that they just ate; who have little control over their behavior; who feel the world owed them because their life did not turn out as well as they would have wished. There are an abundance of American families who because they don't want a home for the elderly or disabled in their neighborhood, report abuse and neglect to discredit a licensed home in order that it can be removed. There are an abundance of local political figures who know they can get votes by pointing out the failures of caregivers and at the same time vote for lower taxes and support zoning restrictions that prevent reasonable and humane caregiving.

SOLUTIONS?

Not all solutions require money, but that is one place to start. It is unreasonable to ask a provider to give high quality care on $15.00 a day. It is very common in licensed homes for the owner to buy shoes, glasses, toothpaste for their residents because a $25 or $30 allowance can't cover such necessities. A quote from a 1985 Pennsylvania document illustrates this problem:

"Currently, the total financial resources available to SSI recipients living in licensed personal care facilities is $472.30 per month. Regulations require that $25.00 be retained for personal allowance. As a result, the amount is reduced to $447.30 or approximately $14.90 per day. Needless to say, $14.90 a day is not adequate to provide food, shelter and quality care. The minimum staffing requirement at minimum wage for a facility of eight residents costs $12.00 per day per client. It is obvious that the balance of $2.90 per day is not adequate to provide three meals, shelter, heat, utilities and insurance. In addition, residents of personal care facilities are stripped of state and federal benefits that would substantially increase their resources. Supplemental Security Income was never meant to be a total resource but rather was intended to be a federal supplement to state benefits."

A quote from the report of an intensive study carried out in 1982 by the Denver Research Institute points out the situation in homes for low income residents.

"In the homes surveyed by DRI, it (the care) was not bad, but it was bleak. No instance of abuse or life-threatening physical neglect of residents was observed. None were found locked in a bedroom or tied to a chair; none were battered or bruised. Because this survey was dependent on the voluntary participation of operators, and refusal rates were not insignificant, it is not possible to state that abuse or life-threatening neglect does not occur in board and care homes. If it does occur, it does so in a minority of homes. The residents observed and interviewed by DRI were occasionally not as clean as our middle-class standards would dictate they should have been, some were inappropriately dressed, and some were in need of a shave. Others, knowing that an interviewer was coming, dressed immaculately for what was for them a very important social occasion. They sometimes competed for the interviewer's attention and often were hurt when passed over. Generally, the mentally ill and the elderly were being cared for by some very caring and conscientious operators who were doing the best they could with the resources available to them."

Provider staff training is badly needed. Many state agencies and state associations are attempting to carry out this function. Our association proposes to do a program whereby not only gerontology content training but also training in how to use available educational resources could be offered to providers. Needless to say, finding available resources to carry out such training has been difficult.

Another solution also requires fiscal resources and the desire to place care of the elderly and disabled as a high priority. There is need for more highly trained licensing inspectors and community support staff. Not only are the direct care staff among the most poorly paid workers in this country, but the people who monitor their facilities also are most often poorly trained. Many licensing people know only the regulation book and concentrate their inspections on the physical condition of a building or the status of records. They do not recognize fear of abuse, over-medication or good care. They cannot give advise because they do not understand care of the elderly or disabled. Our Association endorses the notion of a professional agency to investigate abuse and neglect, but such a professional staff must be well enough

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trained to recognize total problems and not jump to conclusions about abuse. The people in social services are too often undertrained, underpaid, overworked, and demoralized. We have put in place a system whereby caregivers and care overseers are put in a "no win" situation. They both also have the right not to be programmed for failure.

Are we going to make care of our most vulnerable citizens a real priority in this country or are we going to let it continue to slide out of control?

The hearing today has pointed out some failures in our society. We would recommend a congressional hearing to tell of the successes. How can quality care providers be encouraged to continue their enterprise? what ingredients go into the environments of happy and fullfilled elderly and disabled? How and what can families and caregivers learn from these successes? What choices need to be made to foster the kinds of life situations for the elderly and disabled with which we can all take pride? The National Association of Residential Care Facilities will happily put its energy into such a hearing and continue to work for quality services within our industry.

Ms. CRAVEDI. Thank you, very much. And rather than asking you to respond to questions from staff, I hope that you will be able to respond to questions that we will submit to you following today's hearing.

Thank you all for coming.

[Whereupon, at 2:45 p.m., the hearing was adjourned.]

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[1] The following are the annotated results of an internal federal government study of nursing homes around the nation identified by the Health Care Financing Administration as "troublesome" in 1984. Each of the 10 HCFA regional offices were asked to identify as many as 15 nursing homes which should be candidates for enforcement actions. The following charts contain selected characteristics of these facilities as well as recommended actions to deal with these nursing homes.

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APPENDIX 1

Internal Health Care Financing Administration Analysis of 126 "Troublesome" Nursing Homes Around the Nation [1]

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REVIEW OBJECTIVES

-IDENTIFICATION OF COMMON CHARACTERISTICS

-HOW AND WHY PROBLEMS PERSIST

-EVALUATE EXISTING PROCEDURES-
WHAT CHANGES NEEDED

-FORMULATE REMOVAL CRITERIA

150

SCOPE / METHODOLOGY

— 126 LTC facilities reviewed

— 8-15 Troublesome facilities in 10 Rgns-38 States

— Selection based on:

- Regional experience
- History of poor performance
- Mcare/Mcaid Auto Cert System (MMACS) Data
- Freq of adverse actions
- Number of Conds/Stds not met
- Complaints

— Ques completed - State Lic and Cert agencies, Insp of Care Reviewers-73 Total

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126 FACILITIES

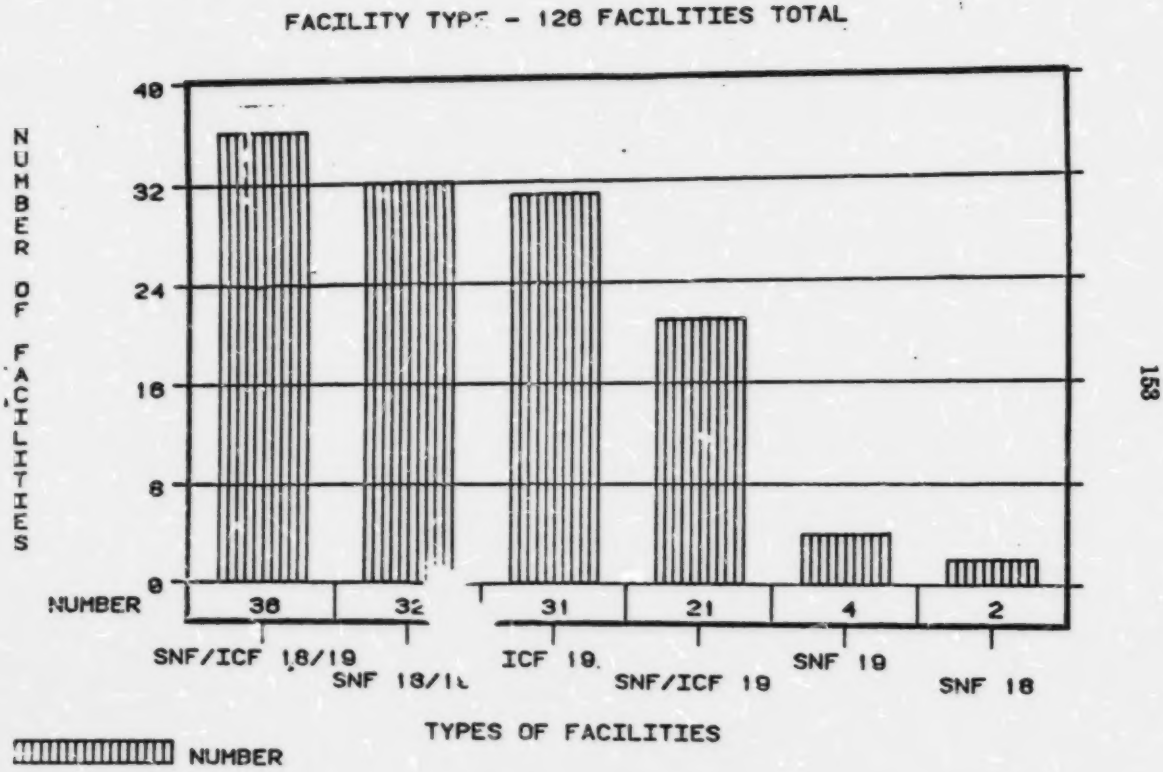
—Averaged 49 deficiencies last survey vs 10 nationally for all LTC facilities

—78% proprietary vs 69% nationally

—71% urban/suburban vs 59% nationally

—46% changed ownership in the last 5 yrs vs 15% nationally.

—46% SNF/ICF dually Certified vs 20% nationally



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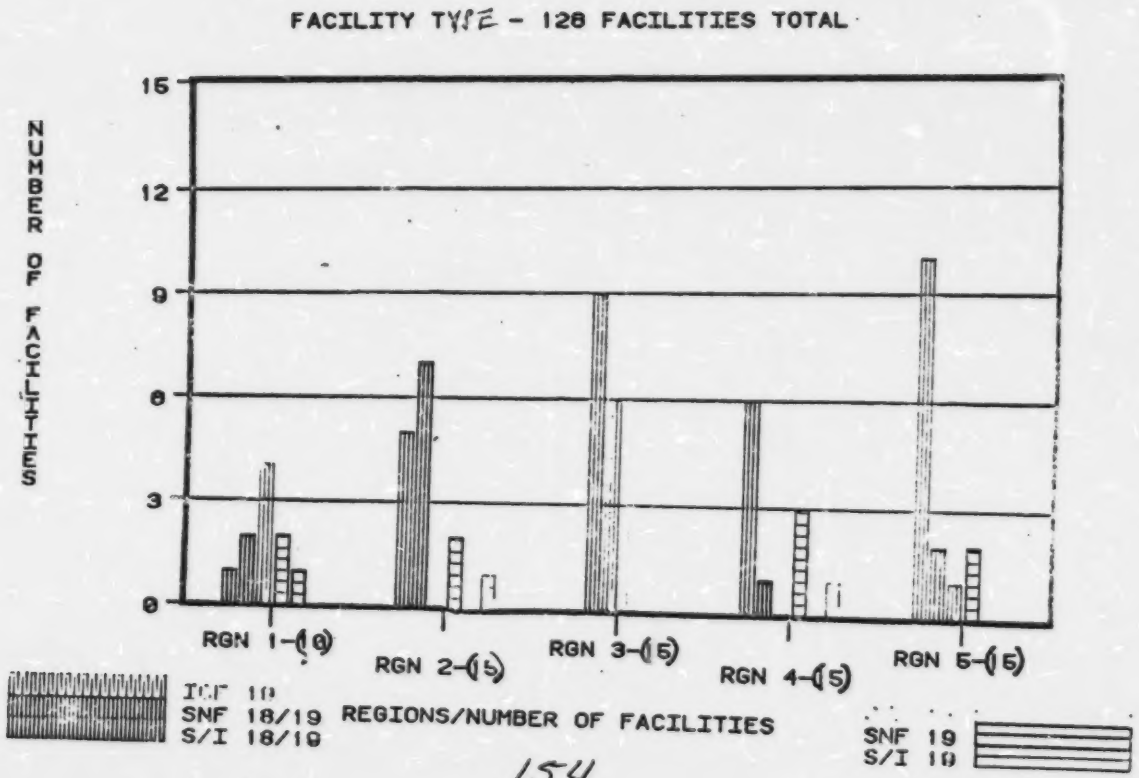

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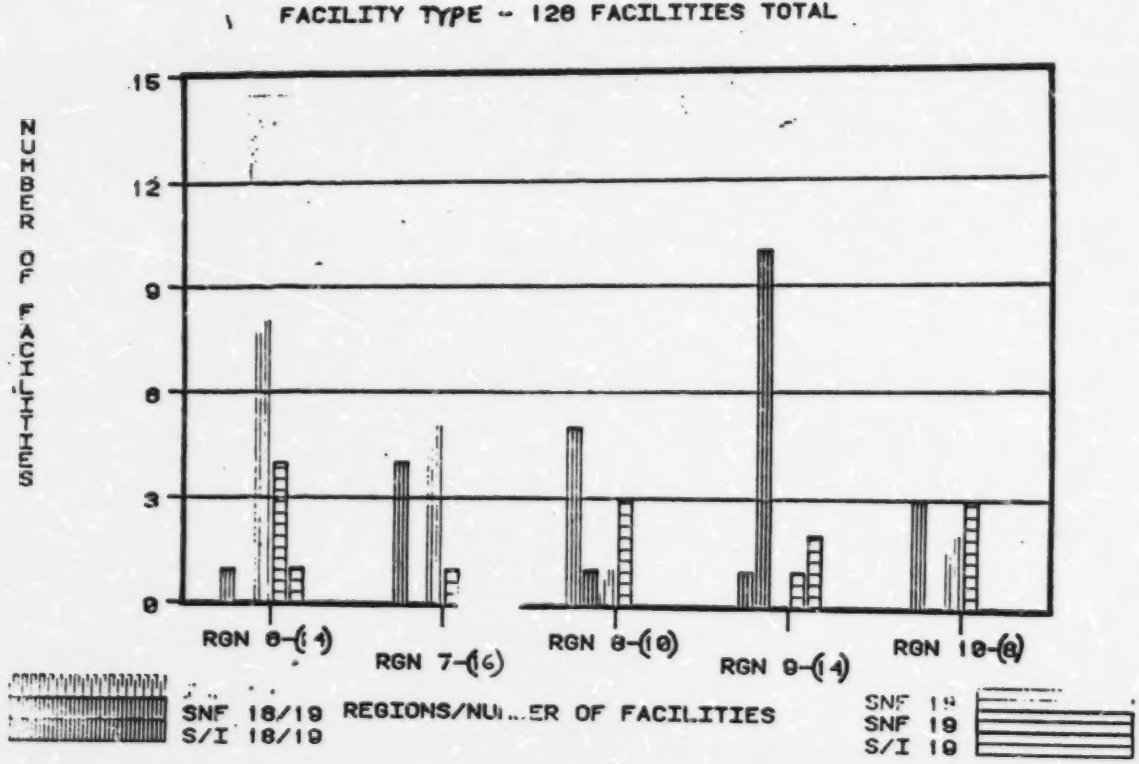

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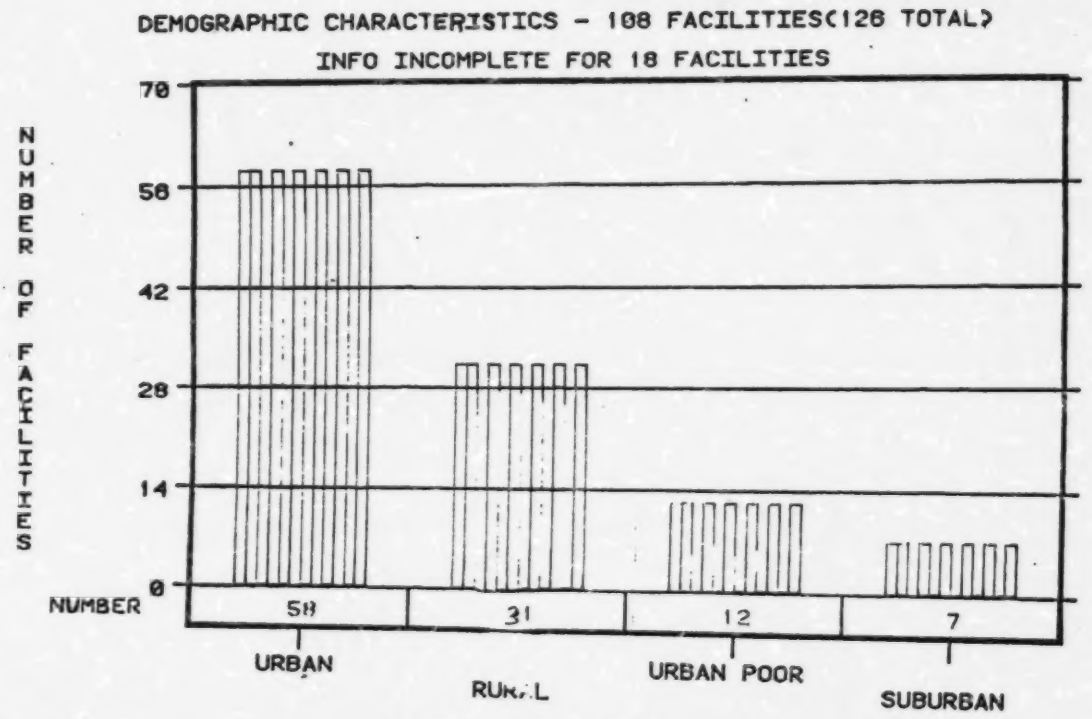

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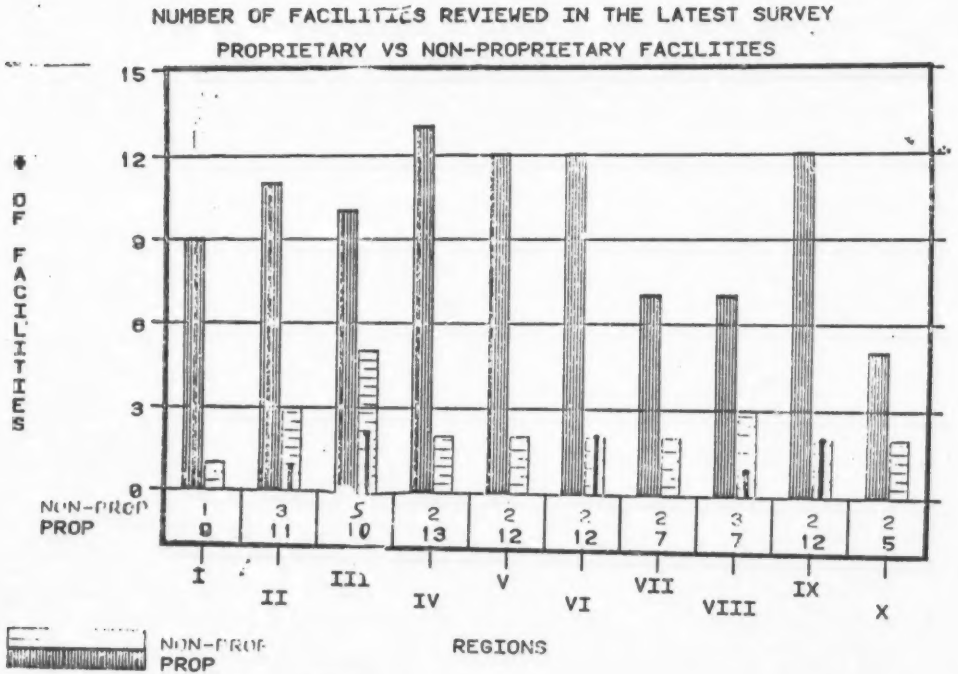

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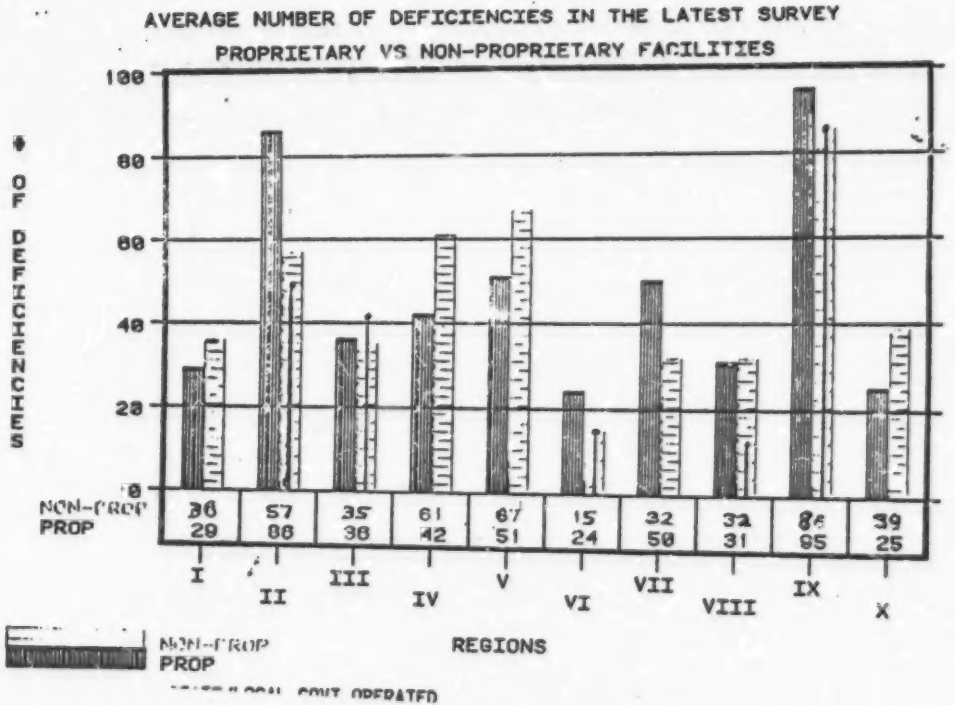

HISTORY OF POOL PERFORMANCE - 126 FACILITIES

- SNFs

—33% HAD 1 OR MORE CONDs NOT MET IN 2 OF LAST 3 SURVEYS

—26% HAD CONDs NOT MET EA OF LAST 2 SURVEYS

— 55% HAD 1 OR MORE STDs NOT MET EA OF LAST 3 SURVEYS

— 67% HAD SAME STDs NOT MET IN 2 CONSEQ SURVEYS IN THE LAST 3 SURVEYS

159

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- ICFs

=79% HAD 1 OR MORE STDs NOT MET EA OF LAST 3 SURVEYS

=77% HAD STDs NOT MET EA OF LAST 2 SURVEYS

=86% HAD THE SAME STD NOT MET IN 2 CONSEQ SURVEYS IN THE LAST 3 SURVEYS

=85% HAD STDs NOT MET IN LAST SURVEY -

160

REGIONAL OFFICE AND STATE DEFINITION OF TROUBLESOME FACILITIES

- REPEATEDLY OUT OF COMPLIANCE WITH CONDITIONS AND STANDARDS
- CONTINUOUS SUBSTANTIATED COMPLAINTS
- PROVIDES A PLAN OF CORRECTION AND THEN PROCRASTINATES
- MAKES MINIMAL CORRECTIONS PRIOR TO DROPPING BACK TO SUBSTD PERF
- NEXT STATE VISIT STARTS SAME SEQ OF EVENTS OVER AGAIN
- POOR PATIENT CARE

161

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CAUSATIVE FACTORS

- HIGH STAFF TURNOVER
- MANAGEMENT PROBLEMS
- LACK OF FINANCIAL RESOURCES
- CHANGES OF OWNERSHIP

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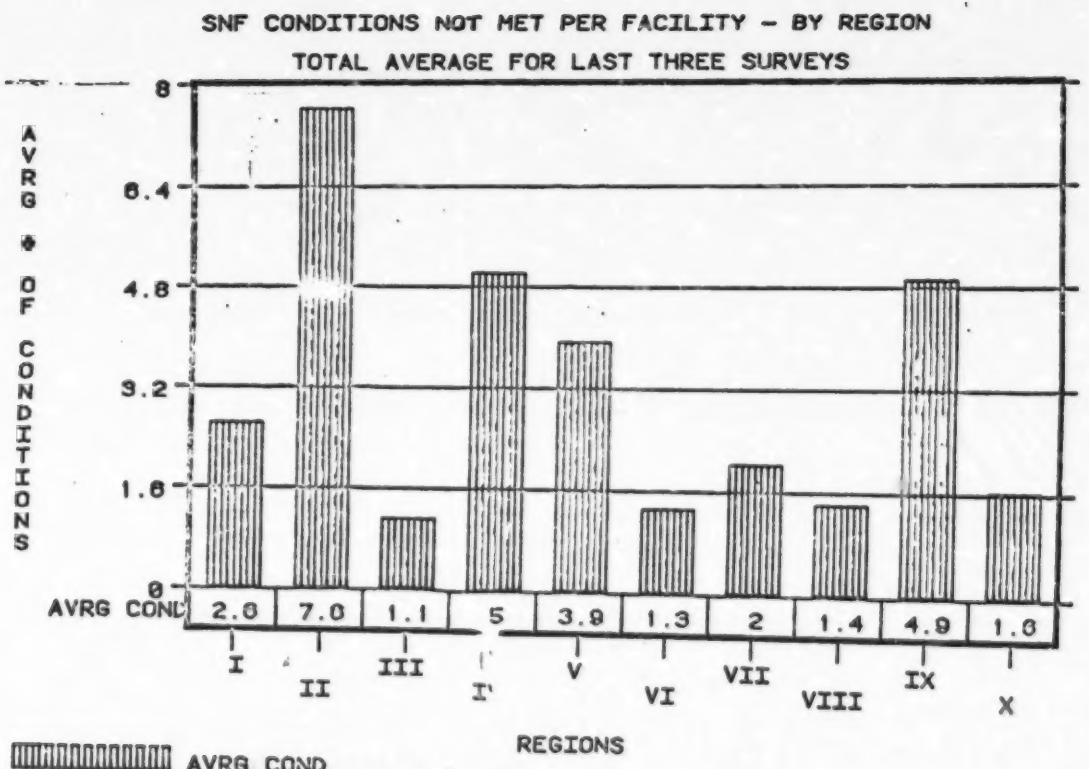

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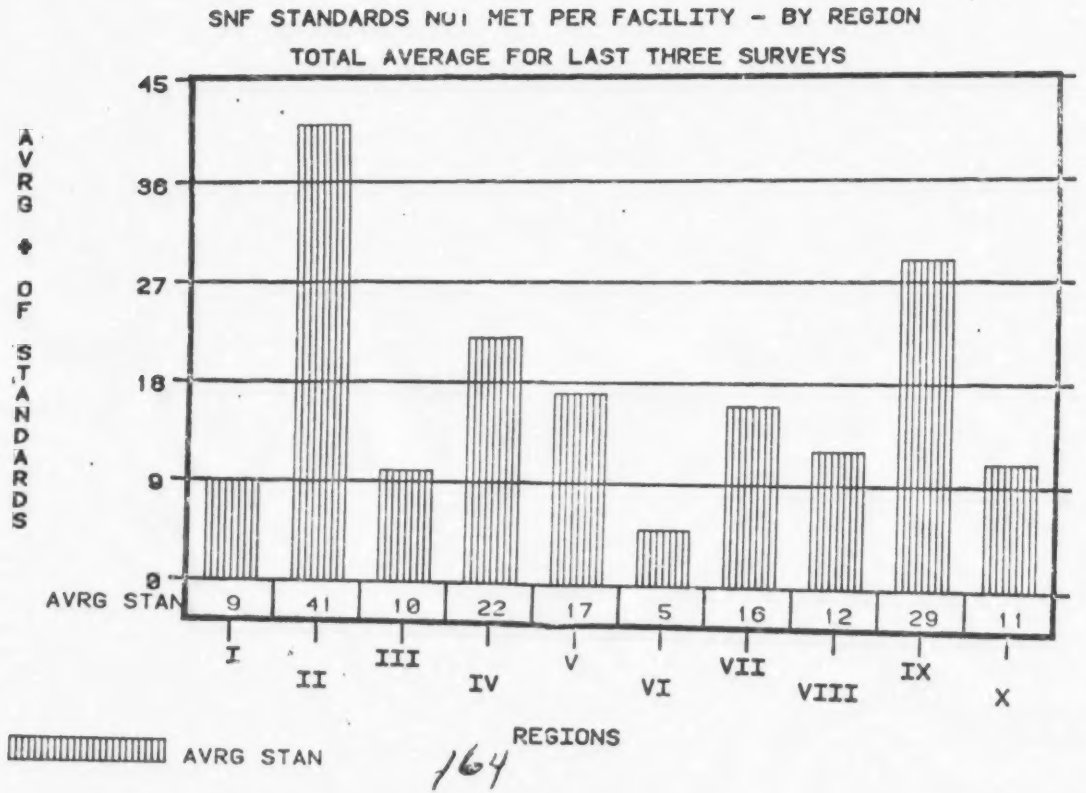

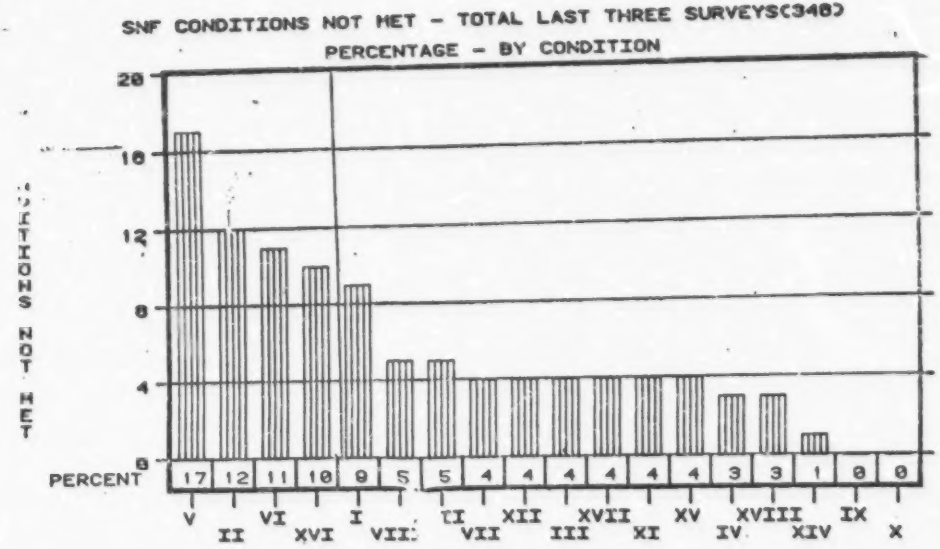
SNF CONDITIONS NOT MET - TOTAL LAST THREE SURVEYS(3480)
PERCENTAGE - BY CONDITION
20
16
12
8
4
0
CONDITIONS NOT MET
PERCENT
17 12 11 10 9 5 5 4 4 4 4 4 4 3 3 1 0 0
V II VI XVI I VIII XI VII XII III XVII XI XV IV XVIII XIV IX X
CONDITIONS
PERCENT

V - NURSING SVCS
II - GOVERN BODY
VI - DIET SVCS
XVI - INFECTION CTRL
I - FED/STATE/LOC LAWS
VIII - PHARM SVCS

XI - STAFFING
VII - SPEC/REHAB SVCS
XII - PATIENT ACT
III - MED DIRECT
XVII - DISASTER PREP
XI - SOCIAL SVCS
XV - PHYS ENVIR

IV - PHYS SVCS
XVIII - UTIL REV
XIV - TRANS ARR
IX - LAB/RAD SVCS
X - DENTAL SVCS

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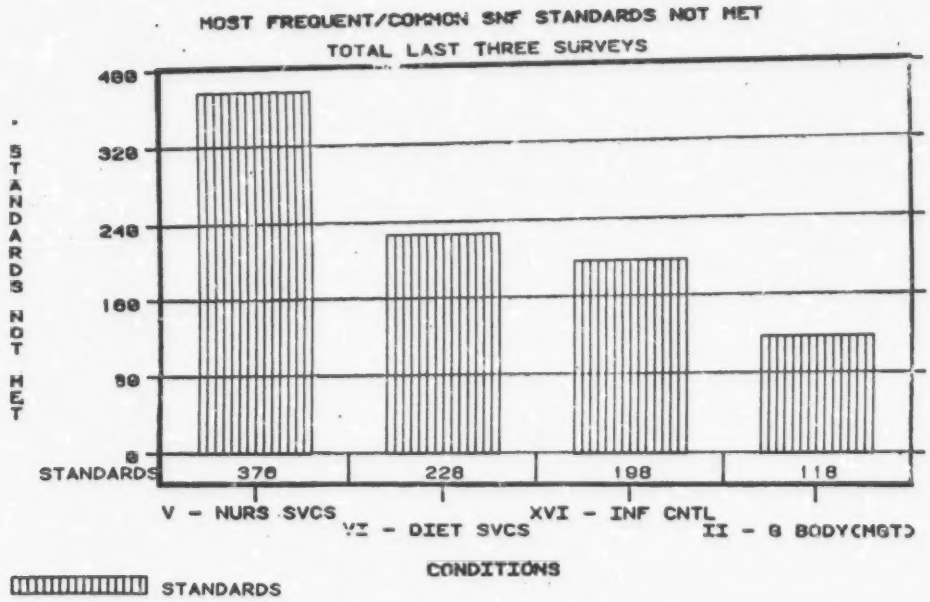

MOST FREQ NOT MET - 920
ALL OTHERS - 955
TOT NOT MET - 1875

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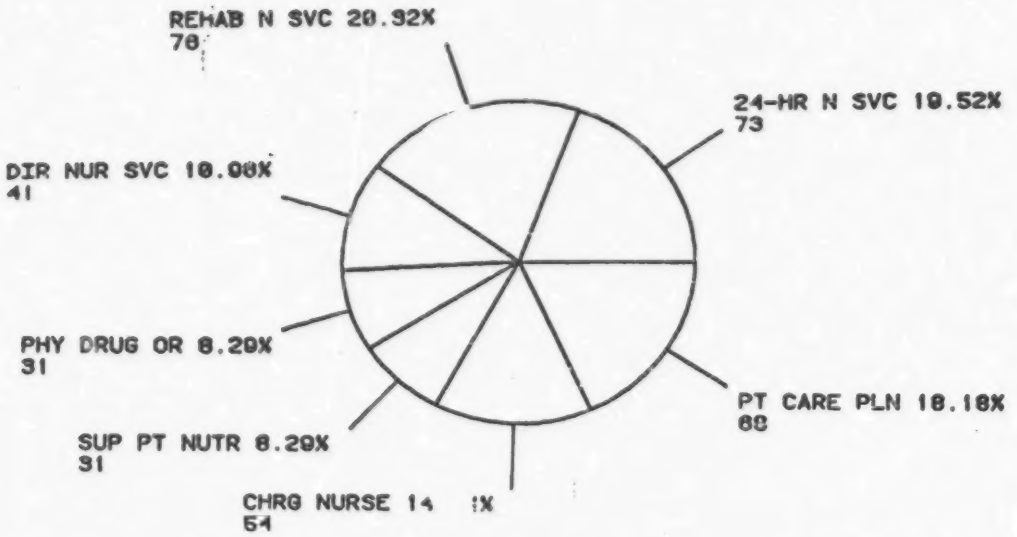
COMMON SNF STANDARDS NOT MET

CONDITION V. NURSING SERVICES



TOTAL STANDARDS NOT MET - 376

REPRESENTS 41% OF THE 4 MAJOR COMMON CONDITIONS

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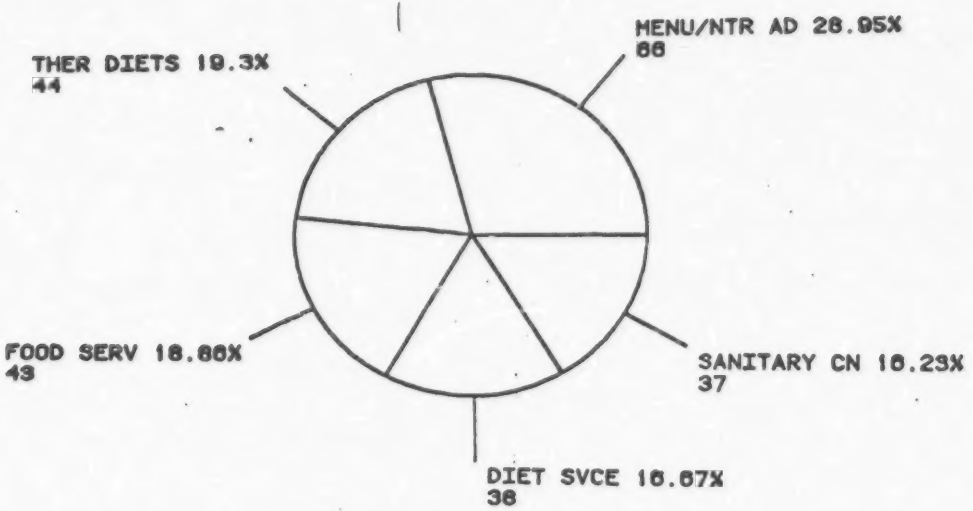
COMMON SNF STANDARDS NOT MET

CONDITION VI - DIETETIC SERVICES



TOTAL STANDARDS NOT MET - 228

REPRESENTS 24% OF THE 4 MAJOR COMMON CONDITIONS

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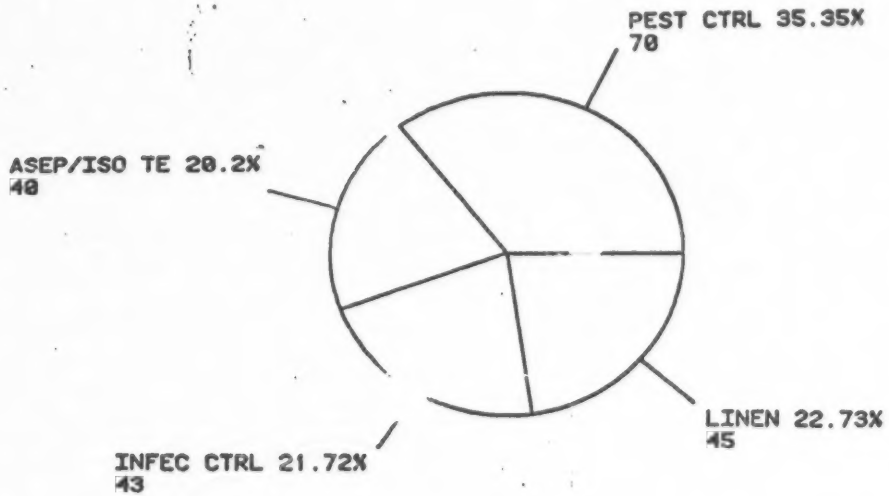
COMMON SNF STANDARDS NOT MET

CONDITICN XVI - INFECTION CONTROL COMMITTEE



TOTAL STANDARDS NOT MET - 198
REPRESENTS 22% OF THE 4 MAJOR COMMON CONDITIONS.

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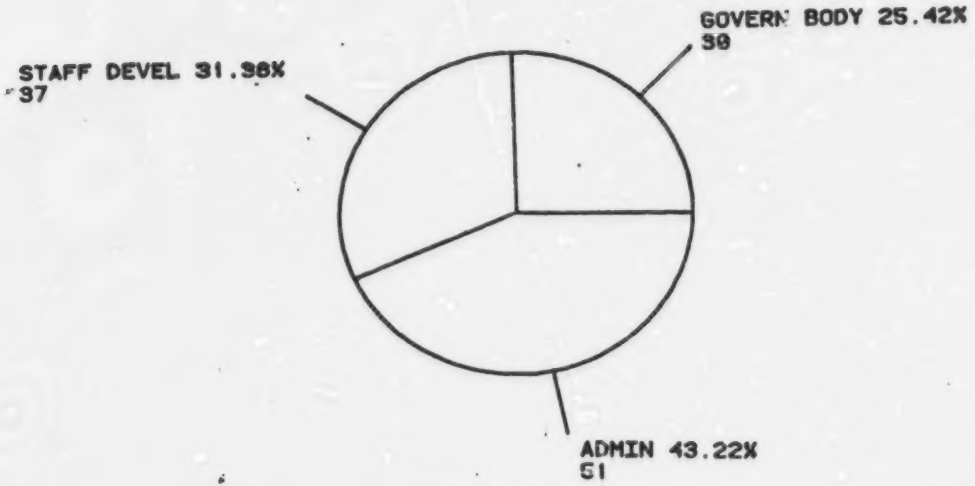
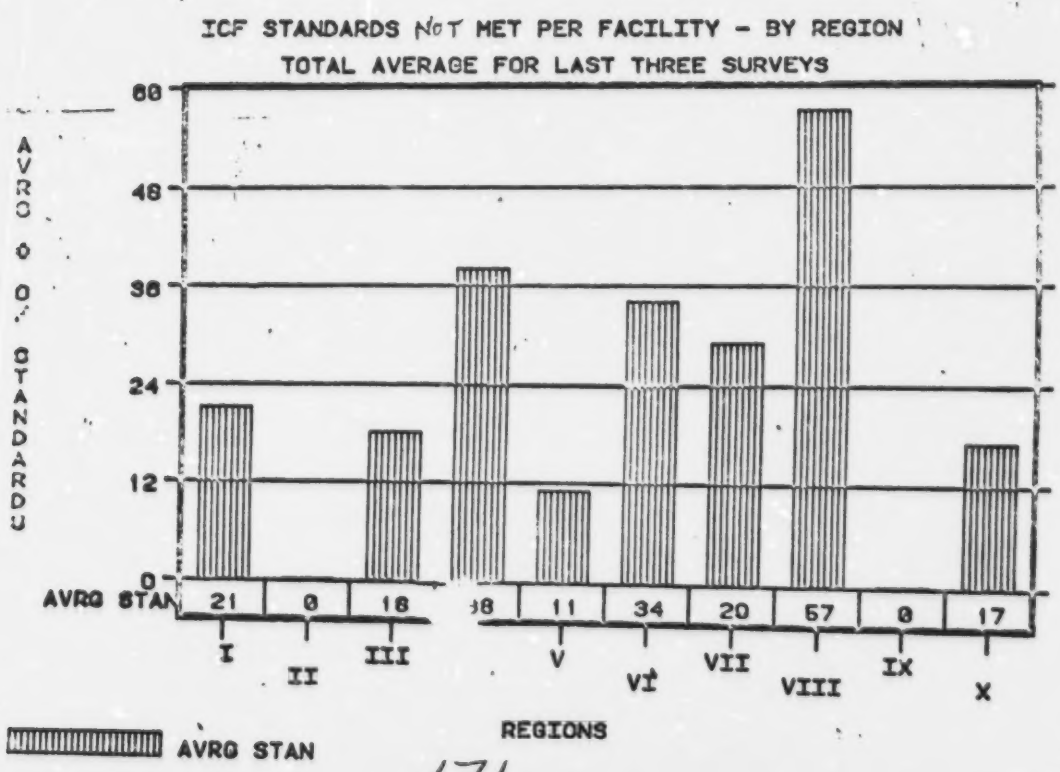
COMMON SNF STANDARDS NOT MET

CONDITION II - GOVERNING BODY



TOTAL STANDARDS NOT MET - 118
REPRESENTS 13% OF THE 4 MAJOR COMMON CONDITIONS

170



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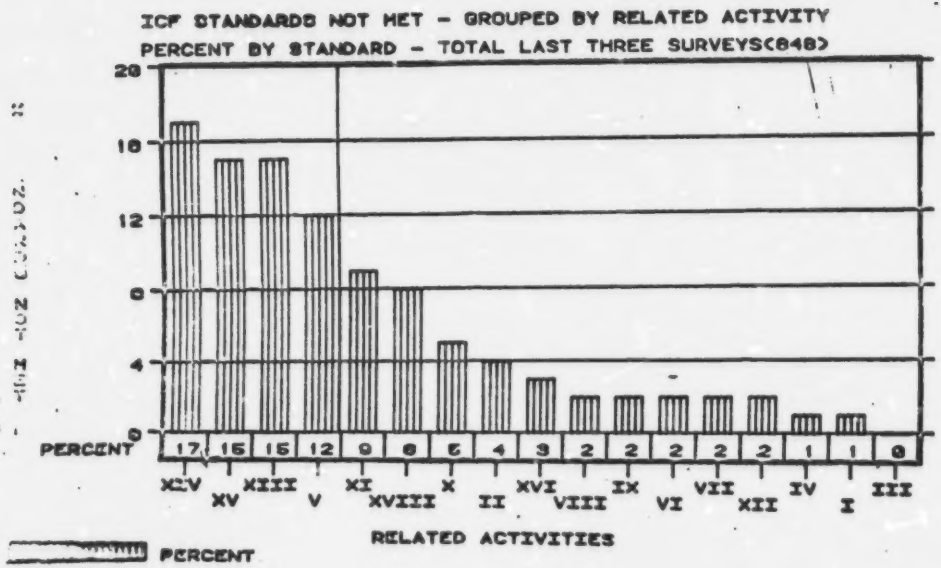
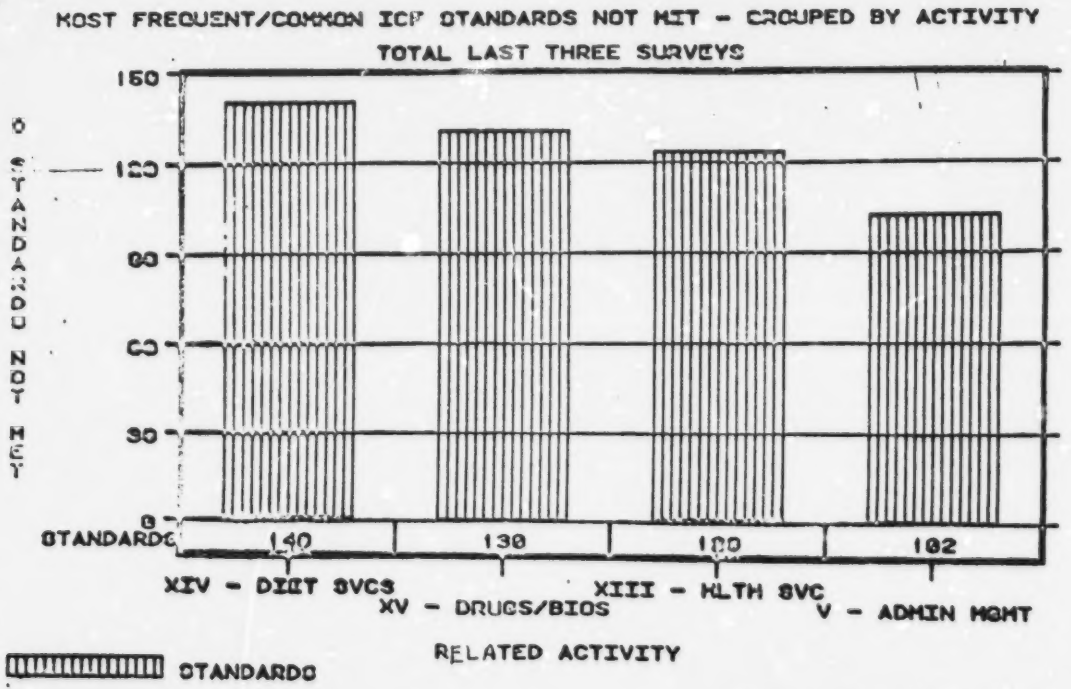

ICF STANDARDS NOT MET - GROUPED BY RELATED ACTIVITY
PERCENT BY STANDARD - TOTAL LAST THREE SURVEYS(848)
20
16
12
8
4
0
PERCENT
17 15 15 12 9 8 5 4 3 2 2 2 2 2 1 1 0
XIV XV XIII V XI XVIII X II XVI VIII IX VI VII XII IV I III
RELATED ACTIVITIES
PERCENT

XIV - DIET SVCS
XV - DRUGS/BIOS
XIII - HLTH SVCS
V - ADMIN MGMT
XI - ACTV PROG
XVIII - ENVIR/SANI

X - SOCIAL SVCS
II - CONFORM W/LAWS
XVI - RES RECORD SYS
VIII - ARRANGE SVCS
IX - REHAB SVCS
VI - ADMINISTRATOR
VII - RES SVCS DIRECTOR

XII - PHYS SVCS
IV - TRANSFER AGREE
I - STATE LICENS
III - DISCLOSE OWNER

172



MOST FREQ NOT MET - 495
ALL OTHERS - 355
TOT NOT MET - 840

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173

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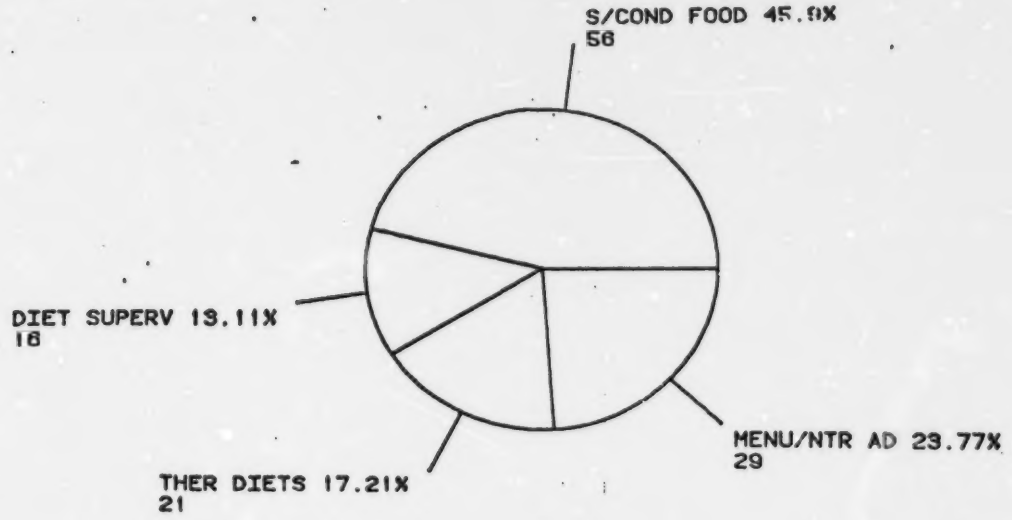
COMMON ICF STANDARDS NOT MET

RELATED ACTIVITY - DIETETIC SERVICES



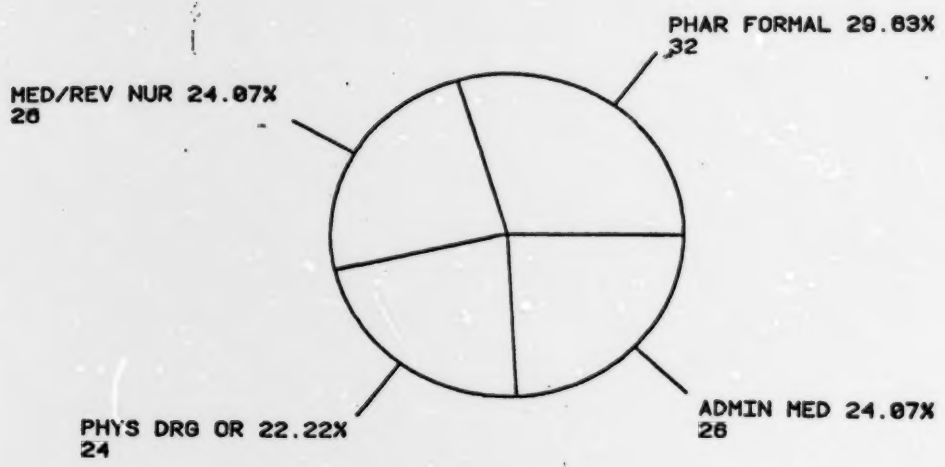
TOTAL STANDARDS NOT MET - 122

REPRESENTS 30% OF THE 4 MAJOR COMMON ACTIVITIES

174

COMMON ICF STANDARDS NOT MET

RELATED ACTIVITY - DRUGS AND BIOLOGICALS



TOTAL STANDARDS NOT MET - 108

REPRESENTS 27% OF THE 4 MAJOR COMMON ACTIVITIES

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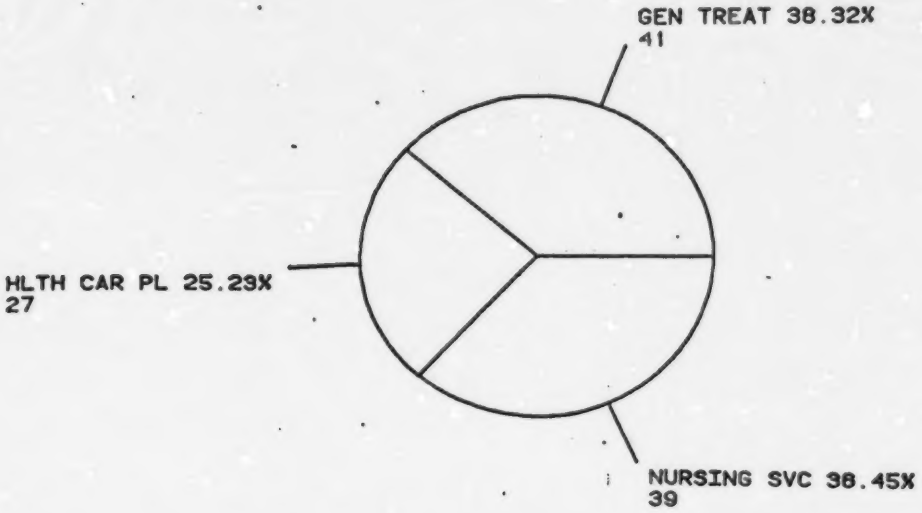
COMMON ICF STANDARDS NOT MET

RELATED ACTIVITY - HEALTH SERVICES, NURSING



TOTAL STANDARDS NOT MET - 107

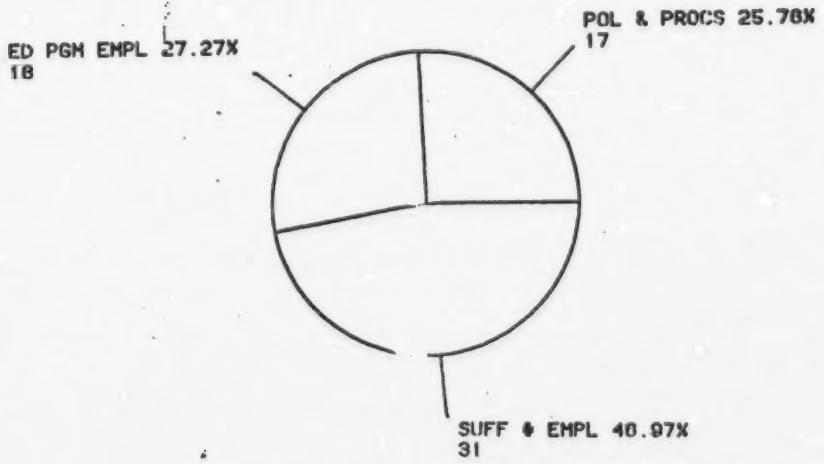
REPRESENTS 27X OF THE 4 MAJOR COMMON ACTIVITIES

176

176

COMMON ICF STANDARDS NOT MET

RELATED ACTIVITY - ADMINISTRATIVE MGMT



TOTAL STANDARDS NOT MET - 68

REPRESENTS 16% OF THE 4 MAJOR COMMON ACTIVITIES

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177

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SUMMARY OF COMMON CHARACTERISTICS OF THE 126 LTC FACILITIES

71% URBAN/SUBURBAN vs 39% NATIONALLY

78% PROPRIETARY vs 69% NATIONALLY

46% CHANGED OWNERSHIP IN THE LAST 3 YRS. vs 15% NATIONALLY

46% SNF/ICF DUALLY CERT vs 20% NATIONALLY

DEFICIENCIES 3 TIMES NATIONAL AVERAGE

NURSING STAFFS INADEQUATE TO MEET PATIENT NEEDS

INADEQUATE DIET - UNSANITARY FOOD CONDs

UNSAT PEST, INFECTION CONTROL AND LINEN

POOR MANAGEMENT

UNSAT. PHARMACIST ARRANGEMENTS

178

SNFs

- 33% HAD 1 OR MORE CONDITION MET 2 OF LAST 3 SURVEYS
- 67% HAD SAME STDs NOT MET IN 2 CONSEQ SURVEYS, LAST 3 SURVEYS

ICFs

- 86% HAD SAME STDs NOT MET IN 2 CONSEQ SURVEYS, LAST 3 SURVEYS

77% HAD STDs NOT MET IN EACH OF LAST 2 SURVEYS

- IN AND OUT OF COMPLIANCE

179

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ELIMINATING

BARRIERS

TO

EFFECTIVE

ENFORCEMENT

SURVEY PROCESS

SUBJECTIVITY IN THE SURVEY PROCESS

CONFLICT OF INTEREST

IOC STANDARDS

FEDERAL OVERSIGHT RESPONSIBILITY

PUBLISHING FACILITY DEFICIENCIES

ADHERING TO MANUAL PROCEDURES

STATE ENFORCEMENT PROGRAMS

NEW LOOK BEHIND AUTHORITY

BREAKING THE CYCLE

CONSIDER FACILITY PERFORMANCE HISTORY

NEW RO ADVERSE ACTION PROCEDURES

HSQB PROPOSED STATE AND FEDERAL TERMINATION/SANCTION PROCEDURES

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181

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SUBJECTIVITY IN THE SURVEY PROCESS

- TERMINATION CRITERIA FOR SNFs DIFFERENT FROM ICF TERMINATION CRITERIA
  - SNFs TERMINATED FOR CONDITION LEVEL DEFICIENCIES - OBJECTIVE
  - ICFs TERMINATED IF PATIENTS HEALTH AND SAFETY JEOPARDIZED - SUBJECTIVE
  - REDUCE SUBJECTIVITY BY ADDING CONDITION LEVEL DEFICIENCIES
  - FOR ICFs or RESTRUCTURING SURVEY FORMS

182

- SOME ELEMENT LEVEL DEFICIENCIES IMPACT PATIENTS' HEALTH AND SAFETY, YET ARE NOT SANCTIONABLE

  - CRUCIAL ELEMENT NOT MET YET IN SURVEYORS' JUDGMENT STANDARD MET

  - STATUTORY REQUIREMENT DEFICIENCY NOT MET YET RELATED CONDITION MET

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CONFLICT OF INTEREST

- CONFLICT OF INTEREST SITUATIONS CONTRIBUTE TO SUBJECTIVE JUDGMENTS
  - SOME SURVEY AGENCIES ALSO RESPONSIBLE FOR RELOCATING PATIENTS AND THEREFORE ARE RELUCTANT TO PURSUE DECERTIFICATION
  - STATES LENIENT IN ENFORCING PROGRAM REQUIREMENTS WHEN CERTIFYING STATE AND LOCAL GOVERNMENT OWNED FACILITIES

184

INSPECTION OF CARE STANDARDS

- STATE IOC STANDARDS INEFFECTIVE AND UNENFORCED
  - IOC REVIEW RESULTS NEEDED TO SUPPORT ADVERSE ACTIONS
  - HSQB TO STRENGTHEN IOC PROGRAM

FEDERAL OVERSIGHT RESPONSIBILITY

PUBLISHING FACILITY DEFICIENCIES

ADHERING TO MANUAL PROCEDURES

STATE ENFORCEMENT PROGRAMS

NEW LOOK BEHIND AUTHORITY

185

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PUBLISHING DEFICIENCIES

- STATUTE AUTHORIZES PUBLIC TO VIEW SURVEY RESULTS
  - SURVEY RESULTS ONLY AVAILABLE AT STATE AGENCY AND SSA OFFICES
  - REQUIRE POSTING PLAN OF CORRECTION IN FACILITY
  - REQUIRE NOTIFICATION OF LOCAL NEWSPAPER WHEN FACILITY TO BE SANCTIONED INCLUDING STATE AND FEDERAL LEVEL ALTERNATIVE SANCTIONS

186

ADHERING TO MANUAL PROCEDURES

- 60 INCIDENTS (47%) IN 126 FACILITY FILE REVIEWS OF IMPROPER ACTIONS
  - UNTIMELY SURVEY & CERTIFICATION PROCEDURE ACTIONS
  - DEVIATIONS FROM PLAN OF CORRECTION PROCEDURES
  - AUTOMATIC CANCELLATION CLAUSES USED IMPROPERLY

STATE ENFORCEMENT PROGRAMS

- STATE INTERMEDIATE SANCTIONS VERY EFFECTIVE IN ENCOURGAGING SUBSTANDARD PROVIDERS TO COMPLY WITH PROGRAM REQUIREMENTS
  - 28 OF 38 STATES SAMPLED USE INTERMEDIATE SANCTIONS
  - MANY STATES LEGISLATURES PASSING INTERMEDIATE PROVISIONS

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- 45 OF 73 STATE AGENCIES QUERIED WANT GREATER FEDERAL ENFORCEMENT ROLE
  - 16 STATES SPECIFICALLY MENTIONED FEDERAL GOVERNMENT ADOPTING ALTERNATIVE SANCTIONS SUCH AS FINES, BANS AND INVOKING NEW LOOK BEHIND

    SOME STATES LACK CONFIDENCE IN FEDERAL ABILITY TO TERMINATE A A FACILITY THUS AFFECTING THEIR ATTITUDE TOWARD ENFORCEMENT
- OLD LOOK BEHIND AUTHORITY COULD BE INVOKED WHEN STATES FAIL TO ADHERE TO PROPER SURVEY & CERTIFICATION PROCEDURES
  - 8 REGIONS NEVER DISALLOWED FFP UNDER OLD LOOK BEHIND
  - OLD LOOK BEHIND WOULD ENCOURAGE STATES TO FOLLOW CORRECT PROCEDURES IF THREATENED

188

NEW LOOK BEHIND AUTHORITY

- 7 REGIONAL OFFICES HAVE NEVER INVALIDATED A PROVIDER AGREEMENT UNDER NEW LOOK BEHIND
  - 2 REGIONAL OGC LIMIT APPLICATION TO LIFE THREATENING SITUATIONS
  - 2 REGIONS BELIEVE APPEALS PROCESS TOO CUMBERSOME
  - HSQB PROPOSED NEW LOOK BEHIND CRITERIA

BREAKING THE CYCLE

CONSIDER FACILITY PERFORMANCE HISTORY

NEW RO ADVERSE ACTION PROCEDURES

HSQB PROPOSED STATE AND FEDERAL TERMINATION/SANCTION PROCEDURES

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CONSIDER PERFORMANCE HISTORY

- 7 REGIONS MADE SPECIFIC RECOMMENDATIONS DIRECTED AT FACILITIES WITH A HISTORY OF POOR PERFORMANCE
  - INVOKE REPEAT DEFICIENCY RULE AT 42 CFR 405.1908 AND 442.103
  - LEVY FINES & BANS ON ADMISSIONS ON REPEAT OFFENDERS
  - DO NOT ACCEPT PLAN OF CORRECTION FROM PROVIDERS WITH A HISTORY OF IN AND OUT OF COMPLIANCE
  - TIGHTEN REASONABLE ASSURANCE REQUIREMENTS WHEN A HISTORICALLY TROUBLESOME FACILITY REQUESTS READMISSION AFTER TERMINATION

190

NEW RO ADVERSE ACTION PROCEDURES

- 2 REGIONS IMPLEMENTED TERMINATION PROCEDURES FOR DEALING WITH TROUBLESOME FACILITIES

  - REGION IV

    - o SITUATION #1 TERM. SNF WITH CONDITION(s) OUT ON CURRENT & 2 PRIOR SURVEYS, NO FOLLOW-UP VISIT

    - o SITUATION #2 SNF OUT OF COMPLIANCE WITH CONDITION(s) NO HISTORY OF NONCOMPLIANCE, ISSUE 6 MONTH AGREEMENT, TERM AT 6 MONTH SURVEY IF CONDITION(s) OUT

    - o REGION EMPHASIZED REASONABLE ASSURANCE CONCEPT FOR TERMINATED FACILITIES

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HSQB PROPOSED STATE AND FEDERAL TERMINATION/SANCTION PROCEDURES TO RELIEVE THE PROBLEMS ASSOCIATED WITH TROUBLESOME SNF FACILITIES

MEDICARE, MEDICARE/MEDICAID FACILITIES	IMPACT
o IMMEDIATE OR SERIOUS THREAT TO PATIENT HEALTH OR SAFETY - FAILURE TO MEET ONE OR MORE CONDITIONS - TERMINATE	7.7%
o FAILURE TO MEET ONE OR MORE CONDITIONS - NO IMMEDIATE OR SERIOUS THREAT - APPLY ALTERNATIVE SANCTION	8.6%
o FAILURE TO MEET ONE OR MORE CONDITIONS ON CURRENT AND NEXT 2 CERTIFICATION SURVEYS - TERMINATE	5%

192

192

MEDICAID ONLY	IMPACT
o IMMEDIATE OR SERIOUS THREAT TO PATIENT HEALTH OR SAFETY - FAILURE TO MEET ONE OR MORE CONDITIONS/STANDARDS - TERMINATE	Unknown
o FAILURE TO MEET ONE OR MORE CONDITIONS/STANDARDS - NO IMMEDIATE OR SERIOUS THREAT - APPLY ALTERNATIVE SANCTION	30.6%
o FAILURE TO MEET ONE OR MORE CONDITIONS/STANDARDS ON CURRENT AND NEXT TWO CERTIFICATION SURVEYS - TERMINATE	14.6%

LOOK BEHIND PROCEDURES

- o IMMEDIATE OR SERIOUS THREAT TO PATIENT HEALTH OR SAFETY - FAILURE TO MEET ONE OR MORE CONDITIONS/STANDARDS - TERMINATE
- o FAILURE TO MEET ONE OR MORE CONDITIONS/STANDARDS. NO IMMEDIATE OR SERIOUS THREAT - APPLY ALTERNATIVE SANCTIONS

198

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OTHER CHANGES PROPOSED BY HSQ

- SPECIFIC REINSTATEMENT RULES
- TRACK KEY DATES VIA MMACS
- MANDATE ROs FOLLOW ADVERSE ACTION PROCEDURES OUTLINED IN MANUALS
- CLOSER MONITORING OF STATE SURVEY RESULTS VIA MMACS
- CLOSER CO MONITORING OF ROs REGARDING OLD LOOK BEHIND
- REVISE ROM AND MANDATE ADHERENCE

194

APPENDIX 2

AMERICAN ASSOCIATION OF HOMES FOR THE AGING,
Washington, DC, September 25, 1985.

Hon. CLAUDE PEPPER,
Chairman, Subcommittee on Health and Long Term Care, Select Committee on Aging, House of Representatives, Washington, DC.

DEAR MR. CHAIRMAN: The American Association of Homes for the Aging (AAHA), the national representative of over 2700 nonprofit facilities providing health care, housing, and community services to more than 500,000 older Americans daily, shares the Subcommittee's concern about tragic incidents of neglect and abuse of the elderly. The Association firmly believes elderly abuse must be exposed and stopped. We commend the Subcommittee for providing the September 18 hearing to explore the issue of protecting rights of the elderly, whether they're living at home, in nursing and boarding homes or mental health facilities.

Throughout its twenty-four year history, AAHA has championed residents' rights, particularly their right to be free from physical, emotional, or financial abuse. Our members' concern with the well-being and dignity of their residents is reflected in AAHA's philosophy that aging is a natural process which should not limit or change a person's right to autonomy and to experience life to its fullest. AAHA members are committed to meeting the physical, social, psychological, emotional, and spiritual needs of their residents in a manner which enhances their sense of self-worth and dignity and allows them to function at their highest degree of independence.

As nonprofit organizations, our members share a tradition of charity and public service. Over 75 percent of AAHA homes are sponsored by religious organizations, while the remaining are affiliated with other philanthropic groups. In all AAHA homes, the board of trustees is comprised of local civic leaders who serve without remuneration to develop the facility's policies and programs. Dedicated volunteers are regularly involved, providing amenities and activities which help make nonprofit facilities truly "homes" for their elderly residents, not merely health care institutions. These volunteer efforts establish a vital link of accountability and involvement between the home and its community. Since the founding of our country, nonprofit homes for the aging have served the elderly in an exemplary and caring way without expectation of personal gain or even—in more recent times—corporate profits.

AAHA is alarmed over much of the hearing testimony which tended to characterize all homes for the aging as suspect at best, and criminal at worst, simply by virtue of being "institutions" for the elderly. This type of generalized condemnation from several witnesses of an entire field tarnishes the image of the many excellent homes offering a vitally needed service; has the potential to demoralize the hundreds of thousands of health care workers who strive every day to provide compassionate, concerned care; and fails to distinguish between nonprofit and profitmaking facilities in the field.

Following his testimony, actor Kirk Douglas, the hearing's key witness, was asked if the research on elderly abuse he had done in preparation for his movie role as a resident of a nursing home helped explain why some nursing homes provide good care while others do not. Mr. Douglas said he could sum it up in one word: "Greed." He noted that when turning a big profit is the motive, homes may be understaffed and employees overworked.

Today, nonprofit homes represent approximately 25 percent of the field and, in effect, are an endangered species fighting for existence in an environment of increasing commercialization and corporatization. Currently, there is an annual turnover in nursing home ownership in some states of up to 30 percent; threatening the stability of the industry to the detriment of residents and the community. This turnover has been concentrated primarily in the proprietary or "for-profit" sector. Some experts believe the industry could be dominated by five to ten proprietary chains as early as 1990, limiting diversity and freedom of choice for consumers. The National Citizens' Coalition for Nursing Home Reform has noted, "Our membershop groups report changes in quality following corporate takeover of a facility. Powdered eggs replace fresh eggs, canned vegetables replaced fresh vegetables, linens are limited, and consultant social workers replace facility social workers. Quality appears to deteriorate."

AAHA would be remiss if we left an impression that there are not excellent proprietary homes, but, we must point out that differences exist between nonprofits and proprietaries, both in terms of their "bottom line" and operating practices. A New York study showed that nonprofit facilities tend to be more spacious by almost

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a hundred square feet per bed, allowing an opportunity for greater privacy. Patients in nonprofit facilities have a higher assessed need for nursing care and rehabilitative services and receive a higher volume of care, averaging approximately a half-hour more nursing staff time per patient per day. Nonprofit nursing homes have 22 percent more nursing staff and 62 percent more therapeutic staff than do proprietary nursing homes.

AAHA's nonprofit members believe the quality of the lives of their residents can be enhanced only through this higher level of care and rehabilitation. Unfortunately, nonprofit's higher patient care costs generally have been associated by Department of Health and Human Services officials and many state agencies with inefficient management. However, administrative costs for nonprofits tend to be lower. They spend less of their revenues than for-profit homes on such fixed expenses as equipment rental, buildings, land, and rent, and more on operating expenses for food, drugs, supplies, maintenance, and laundry. This type of spending indicates that nonprofit management is efficient, compassionate, and focused on serving its residents. Higher patient care expenditures are the unavoidable result of nonprofit facilities' commitment to providing quality care the elderly deserve.

Among the hearing's other featured witnesses were two nursing home residents, who agreed that they had seen no abuse in the facilities where they reside. They pointed out, however, that residents' choices about their daily activities are sometimes limited. Dozens of agencies can be involved in the network of nursing home regulation, licensing, and oversight—federal, state and local governing bodies, the court system, and community advocacy groups all can play a role. Physicians also influence a large portion of patient care. Residents' desires often have to be balanced with directives designed to protect and care for individuals. For example, residents may prefer bacon and eggs for breakfast, but find that a physician has eliminated these from their diet. Or, residents may desire privacy during a visit by their spouse, only to frustrated by requirements in the Life Safety Code that prohibit locks on doors. Because of the varying, and sometimes conflicting expectations, needs, and requirements involved in administering nursing homes, AAHA's membership adopted over a decade ago, a "Bill of Rights" emphasizing that residents are entitled to exercise inherent human rights which contribute to the totality of individual well-being and self-respect.

Perhaps the most critical element in assuring quality care to the elderly in long term care facilities are federal reimbursement practices under the Medicaid and Medicare programs. Current federal payments are below the actual cost of care for many providers. Nonprofit facilities with greater expenditures for patient care are penalized by deficient government reimbursement. AAHA urges Congress to consider a reimbursement system which makes adjustment for the case-mix of patients served and varies rates according to resource need, thereby, reimbursing the costs incurred in rendering quality care. Flat-rate reimbursement builds in incentives for providers to deliver the lowest common denominator of care, seriously harming the health and well-being of older Americans.

As noted in the testimony by the former nurse's aide, many of the low-paid workers in long term care facilities begin their jobs lacking basic skills, training, or ability to cope with the stressful nature of their work. Again, without appropriate reimbursement, the requisite number of competent staff can not be hired, trained, or retained. Inadequate reimbursement serves to discourage quality care and diminish the possibility that nursing homes can offer residents the broadest options of services and activities.

For some elderly persons institutional care is the most appropriate for meeting their needs. The Health Care Financing Administration has noted that elderly persons at the point of applying to nursing homes, "typically either lack family members who can meet their long term care needs outside an institution—or their family has already exhausted its capacity to meet their needs." AAHA hopes that no elderly person or family member will be reluctant to seek necessary care for themselves or a loved one out of fear. Many superb nursing homes can be found. They will have an open-door and history of responsiveness to and involvement with their community. They will provide exceptional, compassionate care, protecting the rights and safety of their residents. We urge those who are exploring the broad range of institutional services for the elderly to contact AAHA, or other organizations serving the elderly, for references or resource material which may assist them in selecting appropriate care and high quality facilities.

Sincerely,

SHELDON GOLDBERG,
Executive Vice President.

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AMERICAN HEALTH CARE ASSOCIATION,
Washington, DC, October 1, 1985.

Hon. CLAUDE D. PEPPER,
Chairman, Subcommittee on Health and Long Term Care, House Aging Committee, Washington, DC.

DEAR MR. CHAIRMAN: I am disappointed that the press of other business took you away from your Subcommittee's September 18th hearing on "The Rights of the Institutionalized Elderly" before it concluded. I was particularly concerned that, after hearing from 15 witnesses about the abuses encountered in institutions, you were not present to hear the nursing home industry's point of view.

The fact is, Mr. Pepper, that nursing homes and their 1.1 million employees heard a judgement of "guilty" rendered on September 18th, without knowing the charges against them. Neither the American Health Care Association, nor the 9000 nursing homes it represents, deserved the treatment received in conjunction with this hearing. We were misinformed as to the subject of the hearing, we were given only a few days to prepare for it, the witness list was kept secret from us as was the nature of the data compiled by the committee.

As a lawmaker, you have surely come to appreciate that there are at least two sides to every issue. Unfortunately the "other side," as represented by three provider groups, had the dubious honor of being the very last witnesses on a 5½-hour long agenda. Twelve members of Congress, a standing room only crowd, and all the national media were present to hear actor Kirk Douglas describe his "research" on routine patient abuse and rat-infested conditions in nursing homes. But more were there, including yourself, Mr. Pepper, to discuss the reality of nursing home conditions and the causes of the isolated cases of abuse which do occur.

The American Health Care Association believes, and believes strongly, that there is another side. We believe there were gross misstatements made on September 18th. There was abuse, too: abuse of data. There was also an incalculable disservice done by this hearing to the one and one half million citizens in nursing homes and the millions more who may need to enter a nursing home someday. Although the damage has already been done, the record needs to be set straight.

Much of the data presented in your opening remarks and the accompanying briefing material can, and has been, easily misconstrued by the public and by the media. There was no attempt to differentiate between actual physical abuse, which no one can condone or excuse, and the limitation on certain personal freedoms because one is in an institutional setting. The inability to choose one's mealtimes is not of the same magnitude as physical and sexual abuse. Yet they were combined in your opening remarks as reflecting indistinguishable and common occurrences in nursing homes.

Did you really mean to imply, Mr. Pepper, that crimes are committed daily in long term care institutions, or were you referring to the fact that anyone living in a group setting cannot have baths or meals when they choose? We believe there is a substantial difference. Living in an institutional setting, whether a dormitory, hospital or nursing home, does necessitate compromises, but there was no acknowledgement of this fact.

Secondly, the hearing, including witnesses and cases studied, deliberately portrayed abuse of patients' rights as a nursing home issue, yet the bulk of the data cited and compiled by your staff is from other institutions, a large portion of which are not even licensed or inspected! Further, no attempt was made to balance the agenda, although one could as easily have drawn similar examples from home health services, hospitals and other health care providers and institutions.

Surely you have visited hundreds of nursing homes during your many years in the Congress. You did these homes and thousands of others an injustice by conducting a hearing which paid only lip service to any constructive purpose. The fact is that much can be accomplished in the patients' rights area, but not by creating the most adversarial circumstances possible. We fail to see what purpose is achieved by deliberately withholding the intent and focus of the hearing and performing under a cloak of secrecy more suitable to a grand jury proceeding.

Space does not permit a clarification of every statement made at this hearing or in committee documents, nor can we refute your committee's statistics, which were based on broad extrapolations from telephone interviews and anecdotal data, without seeing the actual data. Nonetheless, we offer for your consideration the following:

Patients' Bill of Rights.—You stated in your opening remarks that "the Congress should require that federal regulations governing nursing home care include a patients' bill of rights in its conditions of participation," and ". . . facilities should be required to be inspected annually and without notice to a facility."

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Facts.—Within the skilled nursing facility conditions of participation for Medicare and Medicaid, there are fourteen specific rights stated under the standard patients' rights (§ 405.1121(k)). The federal standards for intermediate care facilities include a "Residents' Bill of Rights" (442.311), detailing the rights of residents.

Federal regulations mandate that state survey agencies conduct unannounced surveys of all long term care facilities.

Nursing Care in Nursing Homes.—You stated that four out of five nursing homes do not have a registered nurse (RN) on duty at all times, that patients receive 30 seconds per day of care by doctors, 12.5 minutes from registered nurses and 15 minutes from licensed practical nurses (LPN).

Fact.—Federal regulations do not specify 24-hour registered nurse coverage. Most nursing homes do not have *registered* nurse coverage on the 11 p.m. to 7 a.m. shift, because the patients within these facilities do not need such services during sleep periods. However, *all* skilled nursing facilities *must* have 24-hour licensed nurse coverage, that is, a licensed practical/vocational nurse *or* a registered nurse on duty at all times. Most state licensing rules require even higher staffing patterns for long term care facilities.

Duties of Nurse Aides.—You stated that the typical aide in a nursing home cares for 20 extremely debilitated patients a day, performing, in addition to their normal chores, those which should be performed by qualified doctors and nurses. These chores were listed as: preparing and administering oral medications, suctioning patients' throats, inserting indwelling catheters, counting pulses, and suctioning patients' noses.

Fact.—Catheter care and suctioning are tasks which should be carried out by licensed nurses, not aides. I hope that when your staff found aides performing such care, these incidents were reported to the appropriate board of nursing and licensing offices. On the other hand, assessing vital signs including taking pulses, is routinely taught to most aides and they perform such tasks competently. Aides are permitted to give oral medication in thirteen states, but only after completion of a state approved course. A recent study conducted by the Health Care Financing Administration found no correlation between drug errors and whether drugs were administered by medication aides or licensed nurses. No matter who administers the drugs, licensed nurses are responsible for monitoring the side effects of all medications.

Salaries of Nurse Aides.—You stated that nurse aides make an average of $136 per week, while prison guards make $320 per week. This may well be true. The fact is that every year, our association has had to go to Capitol Hill to fight against Medicaid program cutbacks, which have a direct impact on the reimbursement rates paid to nursing homes. In 1982 the rates paid for care of the old and sick in 61% of the states was $35.00 per day or less. The amount paid for the upkeep of a prison inmate in a typical Illinois jail was $42.56 while the state paid only $28.35 for its Medicaid nursing home patients. Is this a statement of the values of our society when we pay more for room and board for a convicted criminal than we do for room, board and nursing care for our poor and sick elderly? In 1982 the average cost of a day in a skilled nursing facility was $42.88 and an intermediate care facility was $35.98. Most of us could not find a hotel for that amount, much less three meals, nursing care and laundry services.

Low Medicaid reimbursement is one of the root causes of low staff wages and resulting problems, such as high staff turnover, occurring in some nursing homes. Until the federal government and the states acknowledge this fact and do something about it, these problems will persist. Special recognition and credit should go to the State of California, which has passed legislation with funds specifically earmarked for increasing the wages and staffing levels of its nursing homes.

Private Right of Action and Increase of Funding for Medicaid Fraud and Abuse Units.—We believe that comment is warranted on two recommendations which were made at the hearing.

Several witnesses suggested that private right of action was one solution to the abridgement of patients' rights. Genuine abuse *is* actionable in civil or criminal court or, often, in both—under existing law. The infringements of patients' rights that are not actionable are those that are difficult to prove culpability. How, for example, could one show that failure to fully recognize the dignity of another individual required some penalty?

A more important modification would be the clarification of existing patients' rights standards. As presently written, they are so vague as to be unenforceable.

Another recommendation was the enactment of legislation requiring state Medicaid Fraud and Abuse Control Units to investigate and prosecute cases of patient abuse and neglect. We believe this proposal is ill-conceived and reflects a misunder-

standing of the term "abuse" in the control units' title and of the functions performed by their staffs.

The abuse investigated by the Medicaid Fraud and Abuse Control Units is program abuse, not *patient* abuse. The staff is comprised of accountants and financial experts, not criminal investigators or experts in patient care.

The role of investigation of patient abuse and neglect is a direct responsibility of the state nursing home ombudsmen, surveyors, and law enforcement authorities. It makes no sense to involve an additional agency with no expertise in this area. Only six days before your September 18 hearings, AHCA testified before the House Aging Committee, Subcommittee's on Human Services lauding the Ombudsman program and recommending increased funding for it. This would be a far more constructive way of improving the program, because it would draw upon and reinforce existing expertise and channels of complaint resolution.

In conclusion, Mr. Pepper, AHCA sincerely regrets the format and style that you chose to publicize what is an important and legitimate concern for 1.5 million nursing home patients. We do not believe that a media event overloaded with emotional and sensational cases and misleading and unverified data, can result in any beneficial or constructive effort to help those patients.

For our part, the American Health Care Association plans to continue in its many education efforts to assist nursing home providers and others concerned with patients' rights and patient care.

Thank you for the courtesy of your time.

Sincerely,

PAUL R. WILLGING, PH.D.,
Deputy Executive Vice President.

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